Healthcare Improvement Scotland | SIGN

Royal College of General Practitioners

NICE National Institute for Health and Care Excellence

Managing the long-term effects of COVID-19
Targeted consultation on draft guideline
Comments table
26/11/2020-01/12/2020

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NICE GP Reference Panel	Guideline	General	I think its too vague and too all encompassing to be helpful. this needs to be an unprecedented research area. much morbidity will be experienced, we need to know if we can affect this by changing the management of acute covid. eg should all have what donald trump had or not? the assessment should be part of what the therapeutic and research team are doing, not a separate part. referral should be replaced with involvement. eg refer for psych assessment? why cant the assessor assess this? there is not evidence for this so NICE should not jump the gun.
NICE GP Reference Panel	Guideline	General	This guidance is quite vague and I realise the reason for this is the lack of any evidence as to what might help these patients. I think it would be very useful to provide a summary for GP's with a list of baseline tests to reasonably consider to exclude other causes [eg basic blood tests and then-if ongoing cough? CXR/CT Chest, if ongoing palptitations 24 hr tape, if sob and CXR clear-check BNP etc.] . We have 10 minute consultations and while ,of course, we will empathise with them, the patients probably also want us to be sure nothing else is going on.
Faculty of Health Sciences, Oxford Brookes University	Guideline	General	The guideline really needs to address the general question of how patients with multiple symptoms and often several disabilities that are persisting, possibly getting worse and possibly improving, should be managed. Covid 19 is simply an example of a problem that is common and is seen in, for example, chronic fatigue syndrome, Multiple Sclerosis, after trauma with injuries, and increasingly in association with ageing. Rather than spending time thinking about post Covid, it would be better to spend the resource thinking about the general problem which would also solve the problems associated with Covid 19 See: https://doi.org/10.1177/0269215520971145
Cardiff and Vale UHB	Guideline	General	We thing that this draft is a good starting point • The Definitions of Acute COVID, Ongoing symptomatic COVID and Post-COVID syndrome are as good as any (but still arbitrary – the 4 illness type model is clinically better but not necessarily as day-day useful) • We are largely happy with the proposed interventions • The focus on self-care with Apps/wearable devices plus MDT rehab/therapy assessment is key. • We are really keen to ensure that Long COID is not over medicalised. We do not support the setting up of secondary care specialist clinics, but rather favour that this is primary care driven, supported by a rehab MDT, with access to expert secondary care advice as and when needed, rather than making this a secondary care specialism. As recovery is likely to be protracted for many it is important to manage expectations , and not seek a "cure" by over investigating and creating dependency. Rehabilitation guided by AHPs , with support from a wider MDT only when needed is key.
Patient Advisory Group to the CFS/ME	Guideline	General	The majority of our comments relate to the problematic exclusion of any discussion of ME/CFS (or indeed post-viral illness / post-viral fatigue syndrome) in the draft guidelines. It is becoming clear that a subset of post-COVID-19 patients meet the diagnostic criteria for ME/CFS. This pattern is not at all unexpected; it has been estimated in epidemiological studies that approximately 70% of ME/CFS

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Research Collaborative (CMRC)			cases are triggered by an infectious agent, such as herpesviruses, enteroviruses, Epstein–Barr virus [https://www.cdc.gov/grand-rounds/pp/2016/20160216-presentation-chronic-fatigue-H.pdf]. Importantly, there is evidence that SARS-CoV resulted in patients developing an ME/CFS-like illness after infection [Moldofsky H., Patcai J. Chronic widespread musculoskeletal pain, fatigue, depression and disordered sleep in chronic post-SARS syndrome; a case-controlled study. BMC Neurol. 2011;11:1–7]. The similarities between symptoms in a subset of post-COVID-19 patients and in ME/CFS has been highlighted by prominent voices in medicine, clinical research, and healthcare, as well by long-COVID patients themselves. A subset of patients who have had COVID-19 and who meet the diagnostic criteria for ME/CFS have received a diagnosis of ME/CFS at some point over the past six months. Other similar patients, if these guidelines are followed, will not. This inconsistent approach needs putting right. Our primary concern is the lack of acknowledgement of this overlap in the draft guidelines. If the guidelines remain as they are, post-COVID-19 patients who meet the ME/CFS diagnostic criteria may face confusion as to which services they should be signposted to, and at worse be at risk of receiving inappropriate treatment. The recently-published draft ME/CFS NICE guidelines recommend against the use of 'any programme based on fixed incremental increases in physical activity or exercise, for example graded exercise therapy' yet these guidelines [P9, L11] direct patients to 'Your COVID Recovery' site which under 'Getting Moving Again' advises increasing amounts of exercise. ME/CFS patients have repeatedly reported harm from this approach. It is clear from the guidance that there is no evidence base to support this 'rehabilitation' approach and as such it should not be offered. In the management section there is nothing about treating symptoms (e.g., pain, orthostatic intolerance, sleep issues) and yet from the experience of ME/CFS patients this can be one of the most effective ways to help. This would be much more effective than the unevidenced rehabilitation approach being pushed. Rather than develop additional guidance it would be better to point to existing guidance such as the draft NICE guidelines for ME/CFS.
The ME Association	Guideline	General	Sorry - I posted these at the start as well as I did not realise there was going to be an opportunity to do so at the end GENERAL It is surprising and disappointing to find that the draft guideline: (1) Has no recognition that some of the common underlying clusters of symptoms being reported in people with Long/Post COVID are exactly the same as those found in people with a post viral fatigue syndrome (PVFS) or ME/CFS The key overlapping symptoms include activity-induced fatigue; myalgia; cognitive dysfunction/'brain fog'; dysautonomia - involving orthostatic intolerance, postural orthostatic tachycardia, postural hypotension; headache; problems with thermoregulation unrefreshing sleep patterns and post exertional malaise/symptom exacerbation. It would be very surprising if this was not

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			the case given the fact that any type of viral infection can trigger a post viral fatigue syndrome and research carried out following previous coronavirus infections has reported that 10% or more of those infected go on to develop a PVFS or an ME/CFS like illness. (2) Contains almost no information on the pragmatic management of the symptoms that are being commonly reported - activity and energy management in particular. This is also very surprising when a new draft guidance from NICE on the management of ME/CFS has just been published for stakeholder consultation. This guidance contains detailed recommendations on the sort of energy and activity management that is applicable to people with a post viral fatigue syndrome (regardless of triggering infection) and ME/CFS in both the pre diagnosis and post diagnosis stages. Link to draft guideline: https://www.nice.org.uk/guidance/GID-NG10091/documents/draft-guideline It should not be left to the charity sector to be providing the sort of detailed self help management guidance on all these common symptoms that people with Long COVID are reporting. MEA guidance on post COVID fatigue and Long/Post COVID syndromes: https://meassociation.org.uk/wp-content/uploads/Post-Covid-Fatigue-Syndrome-and-MECFS-September-2020.pdf OMISSIONS: EPIDEMIOLOGY AND DEMOGRAPHICS Whilst acknowledging that evidence is preliminary and emerging there should be more information on what we currently know about the epidemiology and demographics of COVID. In particular: Most cases are being reported in people who self managed at home with a mild or moderate illness Many are previously fit young adults in their 20s to 50s Cases being reported in children and adolescents as well Female predominance Current evidence suggests that around 10% of people who develop COVID are developing prolonged symptoms - there could be up to 60,000 people with Long COVID DIET AND NUTRITION Why is there no guidance on diet and nutrition, especially strategies that can help to sustain energy requirements throughout the day and encouraging good fluid intake - which can help with orthostatic intolerance
Royal College of Anaesthetists	Guideline	General	Clinicians at the Royal College of Anaesthetists (RCoA) have been advising patients with “long COVID” (mainly with breathlessness/desaturation on exercise) on when to undergo planned surgery. We have no idea whether there is additional risk in this situation, so we suggest: Patients with long COVID may be at increased risk when undergoing surgery. Patients with long COVID who have already been scheduled for planned surgery and who are suffering cardiorespiratory symptoms or who have evidence of renal or other organ system dysfunction should be re-referred for preoperative assessment and guidance from an anaesthetist. We also ask for the inclusion of a research recommendation proposing a prospective, national audit of surgical outcome in patients who have had COVID and those with long COVID.

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Polymyalgia Rheumatica and Giant Cell Arteritis Scotland (PMR-GCA Scotland)	Guideline	General	The guidance as presented is impressive in its coverage, especially when considering patient needs and involvement in decision making. If it can be implemented it would provide a service which would be difficult to fault. Will our current manpower and funding be able to cope without depleting current stretched resources or will the funds be made available to match the need in a way we have not yet seen within NHS and Social Care?
Carers Scotland	Guideline	General	I found the guideline very helpful and clear. My comments relate to the need to ensure that the important role of carers and families is recognised throughout the guideline, identifying where there are opportunities to involve carers e.g. in receiving information and on supporting self management. I have also sought to identify areas within the guideline where practitioners should seek to ensure that carers are referred to or provided with information on carers centres and services, vital supports to individuals whose caring role may have increased because of the symptoms the person is experiencing or indeed have taken on caring for this first time. Practitioners are vitally important in ensuring that carers can access the support they may need. Many carers have been providing care without a break for many months and maintaining and improving their wellbeing should be seen as an important part of the wellbeing of the person. Secondly, there are points within the guideline where there are opportunities to emphasise the need to ensure that appropriate communication support is in place.
UK Doctors Long COVID Group	Guideline	General	There should be greater emphasis of long COVID as a physical condition that requires appropriate assessment, investigation, diagnosis and management, rather than the current emphasis which appears more psychosocial. This condition is not simply post-viral fatigue, to misrepresent it as such will do a huge disservice to the thousands of patients affected in the UK, as well as result in significant clinical incidents of missed pathology to the long term detriment of the patient. The NHS cannot afford an epidemic of long term, chronic disease as a result of early mismanagement of significant pathology in long COVID. To manage long COVID appropriately now may be expensive and logistically difficult, but it is far more cost-effective, and in the interests of UK society as a whole, to do so and prevent the potential implications of an epidemic of chronic disease to the NHS and UK workforce. Introduction: Page 1 Line 8 Who is the guidance aimed at? NICE guidelines normally start with a statement of this o A clear statement of how this guideline relates to NHS England long COVID assessment clinics should also be made. o Page 1 Line 15 The unknown underlying pathophysiology should be acknowledged and specifically refer to the three current theories of persistent virus in immune-privileged sites, aberrant immune response/inflammatory process or auto-immunity.

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Insight IAPT	Guideline	General	with so little known about the longer term effects of COVID-19 these guidelines will grow and develop based on experience and efficacy of some treatments. many of the symptoms of post COVID-19 syndrome mirror other physical and psychological conditions such as Chronic Fatigue, Lupus, post ICU trauma, fibromyalgia there would need to be a similar approach to treating post covid syndrome. with a balance of physical and medical interventions to treat symptoms such as pain, breathlessness but to also treat anxiety linked to health interventions need to be holistic and timely if we are to support people in returning to be physically, emotional and economical state of wellbeing
British Society for Rheumatology	Guideline	General	GUIDELINE V GUIDANCE Appreciate the need for this guidance but given the rigour and evidence base that is usually required for NICE guidelines it feels inappropriate to refer to this as a Guideline. Referring to this as Guidance feels more appropriate to acknowledge that this is an area where evidence is emerging. WORKING GROUP MEMBERSHIP It would be helpful to know who has been involved with writing this guidance and their specific expertise. ACKNOWLEDGING the LACK OF EVIDENCE We very much appreciate the challenges of having to produce guidance at this time about a condition for which there is little evidence, but this should be more clearly acknowledged within the document. WHO IS THE GUIDELINE FOR There is little specifics as to what parts of the guidelines are applicable to primary care (ie GPs) and what is meant for specialist services (ie COVID-19 specialist service).
Royal College of Physicians and Surgeons of Glasgow	Guideline	General	The Royal College of Physicians and Surgeons of Glasgow although based in Glasgow represents Fellows and Members throughout the United Kingdom. While NICE has a remit for England and SIGN is based in Scotland many of the recommendations are applicable to the UK and all devolved nations including Scotland. They should be considered by the relevant Ministers of all governments. The College welcomes this guideline on the management of long-terms effects of COVID- 19 which it believes is relevant and opportune. However. it recognises that this is a rapidly changing field and that this guidance may need to change equally rapidly as we learn from this new disease. It also relevant not to exclude other long-term diseases from consideration as a consequence of or part of the long COVID spectrum. The original Scope for instance excluded the symptom complexes of chronic fatigue syndrome, chronic pain syndromes and fibromyalgia. It is also possible that other symptoms may need to be added. Definitions in terms of state of the disease may need to be reviewed more frequently than usual. (P2 L12-23)
The Poverty Alliance	Guideline	General	In terms of accessibility of documents produced for patient it would be helpful to have public involvement in this process including representation from patients across different equality strands.

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NICE GP Reference Panel	Guideline	General	First a huge well done for the collaborative effort on this - it is crucial that we have a unified guideline across the whole of the UK so we all, as close as possible, work to the same aims and objectives. My usual plea - please remember that much of the proposed interventions will not be accessible to the vast majority of GPs/primary care practitioners for months if not years, and the admirable desire to have MDT clinics set up is aspirational, and possible unachievable in many areas. CCGs are not beholden to implement any of the proposed clinics which can leave GPs stuck. We need to have advice that can be used by us as 'plan B' if/when this happens. What can we do for our patients now and in the next 6 months? Please see my comments on the self management for example - what resources can GPs access now to help guide patients for self management as we are still likely to shoulder the burden of much of the symptomatology post acute covid. Thank you.
Chartered Society of Physiotherapy	Guideline	General	Is this whole guidance for management across all settings or primarily for primary care / general practice? Who are the target audience? It is descriptive for pathways Will there be different versions for various audiences (lay / clinical), and will there be implementation guidance? There are no recommendations for the use of assessment and/or outcome measures to record symptom progression and final outcome. Section 5: Consider access to self-management support for those that do not have internet, pc access and how this may lead to exclusion. This needs to include recommendations for 1) evaluation of services and service organisation and 2) involving patients in service design and in evaluation.
Royal College of General Practice England, Wales, Scotland and Ireland	Guideline	General	Can the committee consider adding an appendix to the guideline that lists the symptoms that are most commonly found in PCS with the percentages? This would help clinicians identify patients more easily without having to read all of the published evidence. In addition, a visual aid to define the timeline and common presentations would be helpful
Long Covid Wales	Guideline	General	General comments: We welcome this draft guidance, especially the fact that is has been prepared by working with those with lived experience of COVID-19 and its sequelae. We support in particular, that: • This guidance is to be ‘living’ and thus change as this new disease is better understood. • Laboratory tests for acute COVID-19 do not need to have been performed, nor found to be positive, in order to diagnose long COVID. • Patients should not be dismissed when seeking help. Aside from unnecessary harm, we suspect that considerable ascertainment bias has resulted from this most unfortunate

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			attitude. • Specialist multidisciplinary clinics for both diagnosis and rehabilitation should be set up, with a primary focus on diagnostics, which not only can assist those in primary care from managing their patients, but also provide appropriate access to specialist diagnostic services, as well as feeding into research. Comments related to the introduction: This needs a context statement. Presumably this guideline is aimed at primary care, however this is not mentioned. Furthermore, how does this link in with the NHSE Long COVID assessment clinics? It would be reasonable to comment in the introduction on the lack of current understanding of the underlying pathophysiology and the current hypotheses, including, but not limited to, viral persistence (see https://www.biorxiv.org/content/10.1101/2020.11.18.388819v1 and https://www.biorxiv.org/content/10.1101/2020.11.03.367391v1) in immune-privileged sites, excessive inflammatory response, or autoimmunity (https://www.immunology.org/sites/default/files/BSI_Briefing_Note_August_2020_FINAL.pdf). Regarding line 9-10 (page 1), this needs to cover asymptomatic COVID-19 infections who later go on to develop Long COVID, as well as those who relapse; those who initially appear to have recovered from COVID-19 and have a period of feeling back to normal health but at a later stage – ranging from weeks to months – suffer recurrence of, and development of new, symptoms progressing to the development of Long COVID. Comments related to the terms of use in the guideline: Regarding the red flags (page 2), this section is somewhat confusing; it appears to reflect a lack of understanding of Long COVID and its associated conditions. It should mention that significant organ pathology, as well as autonomic dysfunction, due to viral damage must be appropriately investigated for. Regarding line 15 (page 2), the signs and symptoms referred to would need to be listed. It should also include a comment noting that the list is not exhaustive owing to the developing nature of this illness. Regarding line 17 (page 2), alternative diagnoses would need to be defined. How is organ pathology found in patients with Long COVID to be managed? For example, is myopericarditis following an acute COVID-19 infection considered as a subcategory under the umbrella of Long COVID (our preference, as it enables a more holistic approach to management, which we believe is appropriate when managing multi-system diseases), or is this defined as an alternative diagnosis as referenced to in this sentence?
UEA/Fifth Sense/The Norfolk Smell and Taste Clinic	Guideline	General	please ensure smell and taste loss are mentioned in the guidelines

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Patient-Led Research for COVID-19	Guideline	General	We appreciate the panel’s attention to patient-centered care. The recommendations for holistic assessment of the patient, recognizing the ways in which this multisystem condition can interact to impact quality of life, is essential in effective care for Long COVID patients. We also appreciate the panel’s attention to the testing barriers Long COVID patients face, noting that a diagnosis of Long COVID nor admittance to Long COVID care clinics should not be limited by positive PCR/antigen/antibody test results. The panel’s recommendations for proactive follow-up care to COVID patients including recommendations to provide additional support and extra time in consultations, along with the recommendation to partner with community leaders of vulnerable groups to raise awareness about Long COVID are excellent and represent an ideal model of care for Long COVID. We have concerns that the 1-minute sit-stand test may not capture an accurate function level of Long COVID patients. We know that Long COVID patients experience a wide range of multisystem symptoms beyond only respiratory symptoms, including neurological symptoms caused by autonomic dysfunction. Dysautonomia International reports a diagnostic delay of 5 years and 11 months for patients with Postural Orthostatic Tachycardia Syndrome (http://www.dysautonomiainternational.org/pdf/PhysicianPatientInteractionInPOTS.pdf) For this reason, we encourage the committee to consider extending the 1-minute sit-stand test to a 10-minute NASA lean test (https://batemanhornecenter.org/assess-orthostatic-intolerance/) on initial evaluation as all Long COVID patients should be screened for orthostatic intolerance considering the potential prevalence to prevent diagnostic delays. We also have concerns that the document does not mention worsening or relapses of symptoms after physical/mental exertion, despite its significant prevalence in Long COVID. Patient-Led Research found 89% of respondents experienced worsening or relapses of symptoms after physical/mental exertion. The percentage of Long COVID patients experiencing this decreases with time (after 6+ months). This is a critical area for teaching self-management to patients, as pacing education such as this material from Royal College of Occupational Therapy (https://www.rcot.co.uk/file/6696/download?token=XiA9qFCs) could help patients manage symptoms more effectively. This is also an area that requires additional research from both rehabilitation specialists as well as in studying natural history and presentation.
British Geriatric Society	Guideline	General	Thank you for the hard work of the authors in producing this document in such a short space of time. It has been very interesting to read the conclusions of the evidence submitted, and to realise that in fact little appears to be known about the presentation of covid in the community dwelling older adults, and even less about the longer term sequelae. Given that this is a cohort of the population who are likely to be affected in large numbers, I welcome the idea of virtual multidisciplinary teams to provide a one-stop

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			shop, but barriers to identification of appropriate older people who may benefit from the MDT will need to be addressed. Of particular urgency is the need to ensure testing is provided at home for older adults with possible atypical acute covid, to ensure they will be adequately treated acutely and will not be missed if they develop ongoing covid symptoms.
The Royal College of Pathologists	Guideline	General	Royal College of Pathologists Feedback on consultation: URGENT: NICE/SIGN/RCGP COVID-19 rapid guideline on the ‘management of the long-term effects of COVID-19’ - consultation documents. Royal College of Pathologists Feedback on consultation: OVERALL CONCLUSION: There is a need for more rigorous evidence for the diagnosis in this document. Please see comments below. General comments: It is clear that an immense amount of effort has gone into compiling two substantive documents which have been issued for pre-consultation. In addition, the listing of the included studies and the evidence tables are both informative, useful to those of us who try and keep up with the literature and extremely interesting, clearly exemplifying the depth to which the authors went to compile the reports. The principal document, "Management of long-term effects of covid-19" is a valuable dissertation on the broadness of the symptomatology of this disease. It brings a welcome and rational approach to defining an extended period of symptomatology within the diagnosis of Covid 19 and leading to a working differentiation between the "acute disease Covid 19" which is considered to be coherent up to the end of four weeks, ongoing symptomatic illness from 4 weeks to twelve weeks "long Covid 19", illness extending beyond 12 weeks "Post Covid 19". The development of this approach to SARS CoV 2 associated disease and the terminology it brings are a welcome analytical approach. However, from a question of the pathological phenotype of prolonged symptomatology, there is a real concern that this does not take into account the need for diagnostic accuracy. This concern applies also to the Equality Impact Assessment document, nevertheless also a well written, informative and useful paper. To imply that it is sufficiently accurate for clinical practice to consider that the patient presenting with symptoms which are "consistent with the diagnosis of Covid 19" has been infected by SARS CoV 2 is simply incorrect. The very diffuse symptomatology generated by SARS CoV 2 infection may be sufficient for inducing the necessary self-solation but is not sufficient for making an accurate diagnosis of viral infection. In order both better to understand post Covid 19 disease and provide appropriate care for patients with this pathology a diagnosis of viral infection is required. In the acute presentation of symptoms consistent with infection the diagnosis should be made by detection of viral antigen or viral genome in respiratory tract fluid. Additionally, in patients with more severe disease requiring hospitalisation a viraemia may be detectable at the time of presentation and, depending upon the duration of illness prior to presentation, acute phase serology, preferably including IgM class

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			antibody detection, may also confirm acute viral infection. If there has been a delay in presentation the detection of viral infection by PCR or antigen detection may not be possible and the detection of seroconversion is the preferred diagnostic modality. Furthermore, if one is intending to give a patient the diagnosis of post Covid 19 which may also suggest to the patient the concept of resistance to further infection, then it would seem wise to use the presence of detectable antibody to confirm the diagnosis of previous SARS CoV 2 infection. It needs to be borne in mind that only appropriate tests should be used, those which have been identified to display insufficient sensitivity in the late convalescent phase or have poor specificity must be avoided. Other general comments received include: 1/ The guidance seems very vague. It does not give any examples of features/ complications/ red flags. I think this is probably deliberate due to the lack of evidence at this time but we wonder how useful it will be for non-specialists who might appreciate something a bit more authoritative. It is very difficult to identify any points that would help to reduce the number of phone calls to the infection services. 2/ This document helps increase awareness among healthcare professionals to be able to recognise and manage patients experiencing the long erm effects of COVID 19 and provide the necessary support. There is however an urgent need to provide and allocate resources as the current supportive network will struggle to meet these requirements across NHS. In addition, we need to raise public awareness as well so that they seek medical help in a timely manner and avoid delays. 3/ It would be worth considering the impact of extra pathology/blood tests etc. that may be needed for identifying and monitoring of post-COVID-syndrome and whether this has been provisioned for. Increased knowledge about the long-term effects across the specialities will result in an increasing number of tests to diagnose and monitor it. Labs are already under increased pressure as it is and so this needs to be reviewed. 4/ Along with the rest of pathology samples, a relevant history and compliance with specimen taking and transport as required in line with guidance should be highlighted to try and minimise possible infection risk to lab staff etc. 5/ In relation to the research, there are a few possible avenues to look at: - What is the impact of post-COVID-syndrome on the levels of immunity to the virus? Or do differing levels of immunity predict the development of post-COVID-syndrome? - What is the impact of post-COVID-syndrome on other long-term medical conditions e.g. diabetes and their management? - How does the natural history of post-COVID-syndrome vary according to patients of different age, different ethnicity and different pre-existing medical conditions? - What is the pathology/mechanism of disease/pathophysiology of post-COVID-syndrome affecting different organ systems - what are the long-term effects on these? Specific comments: A/ Section 1.1: Why only include those who have accessed healthcare? Some who test positive will not access healthcare

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			formally. Everyone who tests positive should be sent the relevant information about recovery etc. even if they do not contact formal healthcare services. B/ Section 3.3: This is not an exhaustive list. E.g. Troponin, Vitamin D and ECG and should be included. C/ Section 4.1: There is no mention of relevant websites and similar resources such as “Your Covid Recovery”. Specific editorial points: 1/ There seems to be a missing question mark on Page 13 under the section ‘Key recommendations for research’. 2/ Line 5 (page 13) - seems to need a question mark after the risk of developing post-COVID-19 syndrome’?’ The Royal College of Pathologists have a Covid Advisory Group and are very happy to work with other involved parties to help address the issues raised in this consultation. If you would like to make use of this group please contact RCPath
Action for M.E.	Guideline	General	It is disappointing to see no mention of the likelihood of developing Myalgic Encephalomyelitis (M.E.) or Chronic Fatigue Syndrome (CFS) following infection. Research has shown that many people with M.E./CFS developed it from infection https://pubmed.ncbi.nlm.nih.gov/26475444/ Those who experience M.E./CFS symptoms need specific care and management, such as pacing. If those experiencing post-exertional malaise, a hallmark symptom of M.E./CFS, stay within this guideline then they may experience a worsening of symptoms and harm from the further tests, 'treatment options' and disbelief. We acknowledge the need for a rapid guideline. However you have removed the patient voice from the process by developing the guideline without clear input and within public view. If this 5 day consultation was conducted in public, although it is such a short time frame you would still have received a wealth of patient experience and knowledge which cannot be found elsewhere. As this is a living document we would expect there to be a further consultation and then review once this guideline is out in the public domain.
Oxford University Hospitals NHS FT	Guideline	General	excellent work. the separation of the complementary skills of psychiatry and psychology shown an unusual degree of sophistication in thinking. I do wonder if you should make more of health anxiety which is emerging as very common in our post-COVID clinic. Also how investigations can make the worse if care is not taken.: see Illness Anxiety Disorder: Psychopathology, Epidemiology, Clinical Characteristics, and Treatment, Scarella, Timothy M. MD; Boland, Robert J. MD; Barsky, Arthur J. MD. Psychosomatic Medicine: June 2019 - Volume 81 - Issue 5 - p 398-407 -
Faculty of Pain Medicine of the Royal College of Anaesthetists	Guideline	General	The Faculty believe that there is value in specifically addressing pain as a consequence of COVID-19, such as joint pain, vascular post-DVT pain, post-viral pain syndromes and post-ITU procedural pain. In addition it would be of worth to investigate if COVID-19 leads to long term exacerbation of pre-existing pain.

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Patient Safety Learning	Guideline	General	ADDITIONAL COMMENTS ON PAGES 1-2 OF THE GUIDANCE Does this guidance also apply to Wales and Northern Ireland? If so can this be made explicit. We feel that there needs to be clarity on the purpose of the guidance and who will use it. Is it for all clinicians in primary and secondary care? For those commissioning and delivering Long COVID clinics? For patients? For employers and the benefits system? The guidance as drafted meets some of these needs but not for all audiences/users. It is difficult to comment on the specifics of the value of the guidance without this clarity. We feel that the guidance needs to explain why there are three distinct phases of COVID and what has informed the timescale between each one. This ‘living guidance’ approach is to be welcomed given that this is a novel virus, and we are learning about its impact and treatment. In order to give assurance that there is a process for regular update as more becomes known (from research, clinical experience and people with lived experience), the guidance needs to include when and on what basis the guidance will be reviewed. There is a mention of targeted areas being reviewed as evidence emerges. We consider that it would not be satisfactory to leave this ‘open ended.’ Patients and clinicians need to know what would trigger the review. RECOMMENDATIONS FOR RESEARCH We also have some additional recommendations for research - Do patients with Long COVID feel they have been well supported? If not, what have been the barriers to accessing the care they need? What would have made them feel safer? MISC ADDITIONAL COMMENTS Due to the symptoms experienced, some patients may also need physical support accessing healthcare, for example transportation to and from clinics or appointments, or mobility aids on arrival.
Public Health Scotland	Guideline	General	The guideline as a framework is well written and clear but the detail is absent. Whilst I appreciate that the evidence is lacking, an introduction with review of what has been reported in the literature in terms of symptoms, outcome, investigations and management plans is needed – otherwise it presumes that the reader is already aware of it all – I suspect that many (including me) are not. Equally, a brief summary on all that is lacking (so the research questions) should come first with an explanation of all that we don’t know, and how this guideline can be applied when the knowledge is not available. If this were published as is I think it would give a false expectation to patients that Doctors were fully aware of the short and long term consequences of COVID are, and they would be expecting significant clinical input despite the services not actually being available. The services need to be developed first or patient trust will be damaged. Should there be consideration to the setting up of assessment clinics that are also research settings ?– so that data can be captured in a systematic manner whilst reviewing patients and management styles be adapted as evidence emerges. Workforce education, especially in primary care, will be essential for health care professional to be able to provide care for this new

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			condition. Post COVID syndrome will have social and psychological impacts - an overly medical model to managing it should be avoided.
The Society and College of Radiographers	Guideline	General	The scope and purpose of the draft rapid guidance is not clear. The document does outline the population to be covered but what are the overall objectives and health questions to be covered? Who are the intended users of the guidance? Stakeholder involvement – the individuals who were involved in the development process are not listed. It is therefore not possible to ascertain if there has been patient and public involvement. There is no detail about the individuals and job roles of those people who reviewed the evidence nor how the stakeholders decided upon study exclusion criteria. It is not possible to assess the rigour of the guidance development. The search methods are not detailed. A summary of the strengths and limitations of the evidence used would be helpful to develop rigour. Despite the provisions of a list of references, there is a disappointing lack of reference to that evidence in the body of the document. It is reassuring to note that this is intended to be a 'living document' that will be updated as further research is carried out.
Science for ME	Guideline	General	The draft gives little information on either the clinical nature of Long Covid or recommended management. We urge the guideline committee to make use of existing guidelines and to ensure that recommendations are evidenced-based. We believe that it is important that the guideline, rather than lumping post-Covid-19 health impacts into a 'Post-Covid-19 Syndrome', clearly separates the likely range of post-Covid-19 health impacts so that management guidance is appropriately targeted. Post-Covid-19 patients with specific physiological deficits attributable to local damage e.g. lung function issues or stroke, should be treated according to existing relevant guidelines with measures such as the provision of advice on self-care for reduced pulmonary function, and stroke rehabilitation. Given the symptom descriptions, the majority of post-Covid patients with multiple symptoms not attributable to any identified damage are very likely to have a post-viral syndrome. Fortunately, the new NICE ME/CFS guidelines (currently in draft form but still fit for use) are reasonably well-suited to the management of these people. We are puzzled by the lack of reference to ME/CFS in the draft guideline and the lack of evidence of a review of post-viral syndrome/ ME/CFS literature, when it is likely that many people suffering post-Covid-19 symptoms would meet ME/CFS diagnostic criteria. If there is a belief that the post-Covid-19 post-viral syndrome patients who meet ME/CFS diagnostic criteria are not best managed under the ME/CFS guideline, this needs to be explained. This would require giving a scientific basis for providing different treatment to people with the ME/CFS symptom cluster following a range of other infections, including other coronavirus infections, from those with the ME/CFS symptom cluster following a Covid-19 infection. The recommendation for management with an emphasis on 'goal

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			setting' looks all too similar to the historic approach to ME/CFS, which is now understood to have been incorrect. There is neither any theoretical basis nor evidence for the utility of exercise or programmes aimed at increasing motivation in the context of post-viral syndromes. We urge the guideline committee not to make the same mistake made for ME/CFS over the past 30 years, mistakes which have caused a great deal of harm. We recommend that Professor Jonathan Edward's testimony submitted to the recent ME/CFS guideline committee at https://www.nice.org.uk/guidance/GID-NG10091/documents/supporting-documentation-3 is reviewed. Perhaps the key point is the confusion between 'objective' and 'means' in terms of recovery. The objective is to be well enough to carry out normal activities. That in no way implies that the means to get better is to increase activity. The most salient feature of ME/CFS is an adverse reaction to exertion (Post-Exertional Malaise), so it makes no sense to treat it by increasing exertion. The evidence from both trials and rehabilitation clinic records (in as much as it is interpretable at all with high dropout rates, lack of recording of harm and inappropriate outcomes), is that exercise and motivational programmes have no effect on the level of activity that can be achieved and no long term effect on clinical progress as a whole. Many people with ME/CFS report suffering short-term and even long-term harm as a result of undergoing therapist-based treatments for which there was no evidence. Given that there is no evidence of effective treatments for post-exertional malaise, the precautionary principle should prevail in the treatment of people with Long Covid with that symptom. We are concerned at the speed with which this guideline is being drafted. Little more than 3 working days is not adequate for proper consideration by affected communities. Without looking more broadly at the evidence reviewed, and lessons learnt, in other relevant guidelines such as the recent draft guideline for ME/CFS, this haste increases the chances of money wasted on rehabilitative efforts that have no evidence to support them, and that have a real chance to harm patients. We hope that the committee will take guidance from those with a well-informed knowledge of ME/CFS, including the major national patient charities, in order to improve this guideline to better serve the significant number of people who have developed, and will develop a post-viral syndrome following Covid-19.
UK Faculty of Public Health	Guideline	General	We acknowledge the excellent job the NICE group have done in such a timely manner on this emerging syndrome or group of syndromes. As such we also recognise the paucity of evidence in many areas limits what can be firmly recommended. We suggest the document references some of the NICE PH guidance that is relevant to healthy living and well being especially for populations (and so primary care networks / ICSs) badly affected by this with high prevalence. Page 2 line 27. Before the start of the guidance on individual management we wonder if any broad epidemiological information

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			could be included or referenced. We recognise this is not necessarily usual NICE practice but in this situation, with such widely diverse sources of potential information, consensus from such an expert group could be very helpful at local level planning clinical and public health responses. Overall we are very supportive of this guideline and hope our comments are helpful to you.
BAME Health Collaborative (BHC)	Guideline	General	This is much needed and will be a great navigational tool for all to use. BAME Health Collaborative is very proud to be a contributor
ME Action UK	Guideline	General	We remain concerned that lumping together what appear to be multiple different clinical entities into this new term ‘post-covid-19 syndrome’ will result in failures of care. We are especially concerned and surprised that this guideline doesn’t once mention the possibility of ME/CFS, despite the evidence you have used demonstrating that fatigue is the most common symptom patients are experiencing (Arnold, D’Cruz 2020, Daher 2020, Dennis 2020, Raman 2020, Savarraj 2020, Andrenelli 2020, Kamal, Xiong 2020, Boscolo-Rizzo 2020, Goërtz 2020, Halpin 2020). This is alongside the mention of post-exertional malaise (albeit renamed here as post-exercise malaise p5, recommendation 2.7, line 15-18), that is now characterised by the three sets of criteria experts use to diagnose ME/CFS as a hallmark feature of ME/CFS. What is the evidence to include post-exertional malaise as a symptom of long COVID instead of an indication the patient is likely to have COVID-19-triggered ME/CFS? Advice on management and care for ME/CFS differs significantly from that of generalised fatigue in other conditions, with a focus on staying within the patient’s ‘energy envelope’. That ME/CFS is missing from these guidelines is therefore an inexcusable omission, especially since other conditions (such as POTS) are rightly mentioned. It is worrying that Salawu (2020) recommends increasing exercise without taking into account the subset of people who will develop ME/CFS and without validation of results. We see no mention in the rationale or evidence to demonstrate that people who meet ME/CFS criteria post-covid-19 should be treated differently than others who develop ME/CFS (as many have after similar viruses, including other coronaviruses). Yet this guideline suggests rehabilitation as usual for these individuals, despite a clear “Do not offer” recommendation against generalised exercise and rehabilitation approaches in the new draft ME/CFS guideline from NICE. People with ME have endured significant harm and stigmatisation by healthcare professionals, and we strongly urge this committee not to commit people who have or are developing ME/CFS post-Covid-19 to the same fate. There are some very good parts of this guideline, such as the clear statement that people do not need to have had a positive lab test for Covid-19 to receive care. However, there must be mention of ME/CFS and the different management strategies needed for this group of patients if this guideline is going to

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			provide appropriate care and improve outcomes. We urge the committee to rectify this omission. In addition, looking at the evidence that the guideline committee used to draw up this guideline, the weight given to psychiatric sequelae appears to be overstated. Mazza (2020) showed a significant proportion of patients self-rated symptoms in the pathological range: overall, 55.7%. However, there were 101 diagnoses of premorbid psychiatric conditions in the 115 participants. Taquet (2020) and Tomasoni (2020) both count the natural anxiety of having a potentially deadly disease and the harm caused by disbelief of doctors as a psychiatric illness rather than a problem with the way the medical profession treats people with chronic illnesses. The majority of the other studies (listed above) rate psychological symptoms below fatigue as an ongoing symptom. It is troubling to find wholesale disregard of evidence used to draw up such an important guideline. Alongside our concern that people with ME/CFS will be diverted away from appropriate care by this guideline, we are concerned that the problem of long term illness being dismissed as anxiety or depression will not be mitigated by this guideline. This is especially true for women, yet this factor hasn't been mentioned in the equality impact assessment. We ask the committee to: 1. Recommend that patients with post-exertional malaise/post-exertional symptom exacerbation or significant fatigue should be assessed against ME/CFS criteria, and if they meet the criteria be directed to the new NICE ME/CFS guideline. 2. Make note in the guideline that prognosis is unknown, and that long term or chronic illness is one of many possible outcomes. 3. Acknowledge that rest is a part of recuperation from all illness, and recommend that advice on the role of rest is given to patients. We hope that you will take on these points.
National Guideline Centre	Guideline	General	Given the short time frame to comment on this rapid guideline only the chair and vice chair of the ME/CFS guideline committee have been able to have input to these comments. We recognise the difficulties in putting out a guideline in a short time frame and with such limited evidence, and understand that the post-COVID-19 syndrome committee would have wanted to write a guideline that was positive and constructive. However we wonder if the harms reported by people with ME/CFS in response to some treatments should have led to a more conservative approach to the recommendations around rehabilitation, particularly for those people where fatigue is a major factor, and where the fatigue is not related to deconditioning secondary to a prolonged ICU stay, for example.
Clinical Effectiveness Southwark	Guideline	General	Very useful guidance. I think it is not quite clear where the responsibility between primary and secondary care lies though.

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British Thoracic Society	Guideline	General	Please include a link to the written information that is recommended to give to patients on their recovery (what to expect, and what symptoms to look out for that would need to be re-assessed) . If this is not done nationally, there is a danger that symptoms may be attributed to post COVID when this is not the case. There is going to be a high degree of diagnostic blindness, especially if the guidance is used for non-confirmed COVID cases. Ensure alignment with research, safety netting and clinical governance (particularly surrounding the oxygen monitoring).
Chest Heart & Stroke Scotland	Guideline	General	Currently there is a gap in terms of recognizing the potential need of carers and family, and the impact that COVID-19 may have on relationships. As a health charity, Chest Heart & Stroke Scotland are aware of the burden of care, the emotional distress caused by isolation e.g. during hospital stay or as a preventative measure, and the potential impact that COVID-19 has on relationships. "My husband has had a multitude of long Covid symptoms since mid April despite not actually having any of the recognized initial symptoms of Covid. Recognition would mean so much to him, as of course would support from the health service." "I live an active lifestyle with 5/6 days a week exercise between raising 4 kids but I was reduced to barely being able to play with my kids never mind any exercise." The Carers (Scotland) Act, 2016, requires that care givers have their own needs assessed in order to provide better and more consistent support. It would be appreciated if the needs of care givers and families could be acknowledged as part of the holistic assessment.
University College London Hospital	Guideline	General	Excellent initial framework. It would be of help to keep a steering committee including stakeholder from tertiary referral centre, working on this. The latter will help facilitating the development of patients pathway as more evidence become available.
Royal College of Nursing	Guideline	General	The proposed guidance is structured well and is a much-needed rapid guidance.
Lesley Macniven Consulting	Guideline	General	Planning care for people with ongoing symptomatic COVID-19 or suspected post-COVID-19 syndrome Too much emphasis on mental health – please explain patients are likely to be misdiagnosed with anxiety etc. Good to see shared decision-making here, and recognition of fluctuating symptoms, but will this and the other good points – like holistic care – definitely be taken on board? Management / Multidisciplinary rehabilitation Regarding safety for rehab, the Coverscan study, and others, show cardiac abnormalities such as myocarditis (requiring treatment with significant rest) may show only on cardiac MRI, with patients having normal bloods, ECG, chest x-rays, and even echocardiograms – and these patients may also be asymptomatic. Support for older people and children This feels quite tacked

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			on – is there any way to embed their experiences more, and to expand this section? Follow-up and monitoring of people with ongoing symptomatic COVID-19 or post-COVID-19 syndrome Ensure home investigation equipment are provided to people who cannot afford them, and that they understand the limitations of these devices. Sharing information and continuity of care I've never been given a copy of a care plan – is that really going to happen? Service organisation Yes to one-stop clinics and rehab, but please note patients mean specialists such as cardiologists, neurologists, allergists, immunologists and gastroenterologists, including experts in ME, MCAS and dysautonomia. Saying 'relevant skills' leaves the door open to the condition being played down. Key recommendations for research Some good research questions here, but take care with the exercise question – it's biased and could easily be inverted. There are no mentions on the guidelines about NOT prescribing GET – this should be in there. There should be emphasis and priority on the blood markers etc used to diagnosing clots and myocarditis, when patients are reporting these despite normal bloods.
Public Health England	Guideline	General	There is specific reference to symptoms that develop during or following the infection which is broad, but the actions imply this is focussed on specific aspects of health. This does need to refer to the impacts on daily function in some way. Otherwise, there is a risk of medicalising quite a lot of people through trying to avoid excluding others The guidance asks the NHS to plan but it is not very clear on the scale. This will need to have some prioritisation of effort. Something on scale would be helpful for service planning (though recognising data on this still patchy), but thinking ahead resource calculator could be something to include in future iterations (eg how many patients per PCN population? – inevitable impact on chest x-rays for example). Positive test result is important going forward for research purposes, but should not be necessary for clinical diagnosis as depends on availability of testing (which may still vary in certain parts of the country depending on what happens in coming weeks) and people's motivations to be tested (soc/ec factors play a part). We have to be pragmatic. Advice on infectivity of patients with ongoing symptoms would be helpful i.e. can we advise them that they are no longer infectious? – antibody testing? This will be important for them and their contacts. Good to see links made to social support eg. Housing, financial, and employment support. Important to highlight that without some clear time limited definitions it will be difficult to achieve a standardised approach to resebackground-color:#f2f2f2;h on "what works" as there will not be standardisation/comparability between different studies. (example in identifying the benefits of dexamethasone which was controversial a distinction between treating in the second stage (beneficial) and in the first stage (not beneficial and possibly disadvantageous). Epidemiology: No mention of the

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			size/scale of the issue. It would be helpful to include something on likely range (or rates expected from current figures) of the different conditions to help with the planning of services.
Sheffield ME and Fibromyalgia Group	Guideline	General	Sheffield ME and Fibromyalgia Group is starting to receive enquiries from people with long COVID. We offer benefits advice, social care advocacy and social interaction. We have set up a local Facebook group for people to be I contact with each other, and we are now in receipt of some funding to support people locally. We have also been working with the local University and rehab centre and hope to be able to undertake a local survey with Public Health Dept to ascertain the incidence in our area. Having followed in detail the many long COVID groups that are now online, there are a sizeable number of people whose queries relate to symptoms that are very similar to our members who have ME/CFS. While this is not true of everyone with long COVID, as some are mostly experiencing longer term respiratory symptoms, the lack of mention of ME/CS is a very serious omission and will contribute to patients receiving poor quality advice. There is a new draft guideline for ME/CFS out for consultation at the moment, and for a significant number of people with long COVID the recommendations in the draft ME/CFS guideline will be extremely relevant and helpful. The new draft ME/CFS guideline emphasises the hallmark symptom of post-exertional malaise/post-exertion symptom exacerbation and the need for patients to manage their activity within their energy envelope. The ME/CFS guideline is highly critical of the poor quality studies that have promoted graded exercise irrespective of worsening of patients' symptoms, which has caused so much harm. Our group considers it essential that those who experience post-exertional malaise or post-exertional symptom exacerbation should be assessed against the criteria for the diagnosis of ME/CFS in the new draft NICE guideline and immediately advised that rest and not 'pushing through' is essential to increase the possibility of recovery. It is essential for patients' quality of life to distinguish between different forms of fatigue. We do not support a new terminology of 'post-exercise malaise' as this will cause considerable confusion among doctors and patients. Post-exertional malaise or symptom exacerbation reflects a recognition that exertion can be cognitive or other forms of non-physical exertion. There is no reference to the importance of a good nutrient-dense diet in supporting post-viral recovery for everyone, but particularly for elderly people, who may be more depleted in terms of their nutritional status. Dietary advice is limited to advising that it's not known if dietary supplements are helpful, however the guideline should at a minimum at least reinforce the basics re assessing quality of diet, ability to cook if debilitated etc. The guideline is inconsistent about its assessment of gender difference. At one point it suggests the severity of long COVID may be greater in men, yet we know that a range of auto-immune diseases are more prevalent among women and that women's symptoms are more likely to be wrongly diagnosed as caused by

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			anxiety. The gender issues in long COVID need much more work but we were limited by time in making a more detailed response. It is heart-breaking to read many times that doctors are dismissing people’s symptoms as anxiety. We strongly urge you to ensure continuity and consistency between this guideline and the new draft NICE ME/CFS guideline.
CDH UK - The Congenital Diaphragmatic Hernia Charity	Guideline	General	In the introduction there is a reference to Red Flags. I feel that this requires further clarification in terms of the constitution of 'serious underlying cause'. A list of known symptoms and definitions (for example MIS in children) would be helpful Recommended research to be considered: Determining vulnerable groups, Virus shedding in long-covid, impact on existing medical conditions and medications, immunity and antibodies. There doesn't appear to be much reference to gastrointestinal effects within the document or general nutritional references.
British Psychological Society	Guideline	General	Overall, The British Psychological Society welcomes this NICE guideline and feel it would be very helpful. 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. 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. 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 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,

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			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
Royal College of Paediatrics and Child Health	Guideline	General	1) The ongoing concern of the lack of mental health services for children was highlighted so suggesting current MH services could manage this as described is unlikely to happen. Any long Covid commissioned clinics for paediatrics would need a MDT comprising of paediatricians, clinical psychologists allied health professionals such as physiotherapists and access to immunological services for interpretation of covid-19 serology. Setting up single clinics which are not resourced to include all the MDT will be unsuccessful. It may be beneficial to begin with paediatric quaternary services which has clear referral criteria covering a defined geography; which must be linked to ongoing research and thorough data collection including outcomes whilst the impact is being assessed. 2) The reviewer noted that for children there should be guidance for defined age bands from birth to 18 years with particular attention to differential diagnosis from other multisystem immune disorders e.g. Kawasaki. 3) This seems a sensible well-argued approach despite the lack of hard evidence. The reviewers view is that the primacy of a holistic approach that is very mindful of psychological factors and encourages a rehabilitation ethos makes sense. 4) The reviewers support this guideline noting that it is useful guidance. 5) The best thing this guideline has done is be really clear that the physical, psychological, psychiatric and social factors are all considered equally. Also, the idea of multidisciplinary clinics where physical and mental health work alongside each other. There are many other conditions where this should be the treatment model, but previous, historic guidelines were written from the 'medical model' perspective e.g. CFS. This is an opportunity to break down this physical/mental health divide and provide models for how services can be commissioned to include all of the above from different providers which the reviewer suspects will be the biggest challenge. 6) Holistic approach is encouraged • Awareness, education and when to seek medical help • Listening to the body and adjusting expectations • Breathing exercise including paced breathing • Physical deconditioning, graded physical exercise and rehabilitation • Learning new skills • Reducing screen time and exposure to media • Building positive mental health • Practising and meditation techniques •

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			Post Covid diet • Adequate sleep and rest • Avoiding smoking and alcohol • To keep socially connected and to connect with nature.
Scottish Intercollegiate Guidelines Network (SIGN) Council	Guideline	General	Essentially it reads like 'good practice points' which are not necessarily supported by robust evidence (understandably). Hopefully the guidance would provide some practical guidance that would help healthcare professionals in managing this condition. Overall the guideline is well considered. The appreciations of the fast moving evidence landscape and the decision to keep it as a living guideline is particularly prudent. Generally, the Guidance is clear and concise with good support for the recognition that different groups are more impacted. However, there is no consideration of the role of social work when assessment, signposting etc. is suggested. In addition:- • There is little reference to mental well-being. This could focus on mental well-being rather than limited to a mental health condition or disorder. There could also be mention of the impact of symptoms on mental well-being and potential barriers to seeking and accessing the relevant supports. • Whilst we appreciate the stated need for a diagnosis, there are concerns that without a previous or current diagnosis of COVID-19 and therefore 'long COVID', people experiencing the symptoms described would not receive the same level of treatment as to those who have not previously been given such a diagnosis. This may be due to having never been tested or not being tested at the 'right' time. • The impact of poverty although mentioned in the EIA, could be given more focus as it underlies so many of the other considered characteristics. • The definition of "holistic" "person -centred" approach does not consider the social model and focuses on health/medical. It could also reference other professionals (social work, third sector services etc.) more clearly particularly in relation to family relationship, employment, and leisure.
MSD Ltd	Guideline	General	MSD welcomes the development of this comprehensive and well-considered guideline.
Mast Cell Action	Guideline	General	In terms of mental health symptoms there is growing evdidence of the impact of covid on the brain, and indeed the effects of inflammation on mental helath, a good working assumption should be that a considerable number of mental health issues may have a biological underpinning.
Clinical Advisors to the Scottish Government (Clinical Guidance Cell, Professional	Guideline	General	Need for clearer recommendations and evidence base Explicit recommendations are necessary, with the level of evidence for each clearly spelt out. Terms such as "think about" are an example of the kind of terminology that should be avoided in this respect. The importance of recognising lived experience Lived experience could be reflected in a statement at the beginning of the guideline describing this. It could also summarise the symptoms experienced given current evidence. It could state the broad expectation for appropriate communication and a holistic approach as per any patient interaction. Terminology and definitions It is appreciated that it will be difficult to tease out how the symptoms are

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Advisory Group)			linked, but identifying the patient cohort is essential. The differences between people with post-covid syndrome and any other post-viral illness should be set out in order that one can distinguish between them. For example post-infectious IBS is a recognised condition at present. The differences will show what should be different about the management approach already adopted for people who have post-viral illness. Initial screening is v reasonable but the method needs to be person centred and evidence. It is acknowledged that in time we may see specific conditions emerge specific to people who have had COVID-19 however identifying this and determining effective interventions seems in the realms of research. The terminology of post-covid syndrome should be examined anew given post-viral syndrome already exists and is well understood. The terminology of post-covid syndrome potentially raises expectations that treatment is available specifically for post-covid symptoms. This may add to the recognised psychological burden. Recommendations based on the predominant symptom (e.g. dysponea) may therefore be more useful for healthcare professionals. Need to explain how the multi-disciplinary approach proposed will work in current context A proactive approach to dealing with patients with ongoing symptoms is welcomed and can create efficiencies. But it is not appropriate to design a guideline that cannot be practically implemented in the current context. To ensure effective practical implementation it is necessary to explain, in concrete terms, how the proposed method of working can be introduced to the NHS within current contexts. In particular: • The level of post-covid syndrome that there will be is not fully clear. • By common consent the NHS is working in unprecedented times of stretch. • Staff resources are not, and cannot be, limitless. • The physical and mental wellbeing of staff is a particular concern. • Clear pathways and co-operation between a broad range of specialities is mandated in this guideline. But some specialities may be especially stretched in what they can provide. • Not all parts of the UK will have similar levels of capacity. • Some of those who fall within the scope of this guideline may already be engaged with services for management of long-term conditions. • Digital technology needs to enable professionals and patients/carers, not replace it and services should be accessible to all. For example, identifying which professionals should deliver and staff the services proposed should be an important priority for the guideline. The role of nurse specialists and AHPs is noted as being especially important. Similarly, explaining the detail of the desired interface between primary and secondary care is important. The dangers of overmedicialisation and the importance of person-centred care These issues should be tackled head-on in the guideline. Whether we should be offering invasive investigations such as blood tests without fully understanding why and without being able to fully interpret “normal” or subtle changes are in the context of post-covid syndrome is open to question. It can be questioned to what extent this is cost effective or following the

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			tenets of Realistic Medicine. To avoid the dangers of overmedicalisation person-centred and individualised care with a highly rehabilitative and asset-based approach is appropriate. This should deliver genuinely holistic physical, psychological and social support. This should be stressed more in the guideline than it is at the present. To give a concrete example, anyone engaged with patients and families, in addition to exploring the impact on individuals in respect of daily activities of living must also take the opportunity to explore impact of social harms such as poverty, inequality, loss of employment, housing and so on, all of which if unaddressed are detrimental to health. The need for research Any service development in this area should be in the context of a research analysis. To divert a scarce resource to an area without any evidence of benefit (accepting we don't know one way or another) should only be done with the intention of informing an evidence base which means robust research is essential. This should be emphasised to a greater extent. For example, there seems to be no guidance on testing for these patients. Some SARS-CoV-2 antibody tests have now been seen to show 97% sensitivity at ~6 months post infection. Only robust research will enable us to see if there are indeed important correlates with this and post-covid syndrome.
Long Covid Support Group	Guideline	General	Thank you for the opportunity to comment on the proposed NICE/SIGN/RCGP rapid guideline on the “long-term effects of COVID-19”. The Long Covid Support Group – which has grown rapidly since being formed on May 2, 2020, and now has over 31,000 members – has submitted a response to the consultation using the requested on-line submission form. The Long Covid Support Group brings together thousands of people living with Long Covid for peer support and advocacy. As experts with lived experience of the pandemic, we welcome the increased attention of the UK government and the medical professions to meet the needs of the growing numbers of people experiencing persistent and intermittent symptoms following acute infection with COVID-19. We recognise the substantial challenges of setting guidelines when, de facto, knowledge of the progress and impact of the condition is limited and constantly evolving. While we value the opportunity to comment on the specific elements of the proposed guideline, the format of the Guideline submissions process does not allow for reflection on the overall approach, about which we have come comments and concerns. On behalf of thousands of people experiencing continued symptoms we wish to raise the following overarching points: 1. The guideline is vague about the purpose and focus of the document, and would do well to express more clearly who the guideline is aimed at, presumably including 111 and 119 advisers, paramedics, GPs and all clinical staff in frontline services, including staff in NHS Long Covid clinics, those working in A&E and specialists. 2. Overall, we find the guideline to contain internal inconsistencies (not only of language) and it fails to provide a compelling picture of the condition itself or to guide professionals as

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			to the optimal response with a clear pathway to care. 3. We reject the proposal to rename (some phases) of the condition as Post Covid Syndrome. No information or evidence has been presented to justify this change which will only cause confusion for individuals and exclusion from services. Without a proper rationale being presented this is a counter productive and totally unnecessary innovation. We urge retention of the name Long Covid for all aspects of the illness beyond the 4 week acute period until adequate evidence can be produced to justify a change of name. This has not yet been done. 4. We strongly recommend that if and when a change of name is considered that this be undertaken in a thoughtful balanced way, with quality consultation, grounded in data and within the context of a global process. 5. We appreciate that the guideline process recognises that this is a new condition, with a rapidly developing evidence base and that the recommendations will be updated as new evidence emerges. However, we are concerned that the actual text of the current draft of the guidelines does not make mention of the fact that the underlying pathophysiology is unknown and there can only be a relatively small body of relevant research to date. 6. Related, we are concerned that the guidelines fail to make reference to the three current theories of persistent virus in immune-privileged sites, aberrant immune response/inflammatory process or auto-immunity. 7. Moreover, we find the case definition to be seriously lacking as it fails to provide a clear indication of the range of symptoms that may be associated with Long Covid. As such health professionals do not have adequate information for the proper care, assessment, treatment and syndromic management of patients. 8. We dispute the proposal to define different phases of the disease (4-12 weeks and 12+ weeks) and do not find that there is any rationale presented for this – and indeed the document is internally inconsistent on these points. As currently drafted, the guideline fails to reflect the complexities experienced by people with symptoms that can persist, evolve and/or new ones develop (even after 12 weeks), a relapsing and remitting evolution seems to be common, and there are many reports that symptoms can be more pronounced several weeks or months after infection than they were in the early weeks. All of this merits more research and understanding so that the natural history can be carefully described, and until such longitudinal studies can report the guideline should provide a clearer description of the complex pattern and range of symptoms experienced beyond the acute stage. 9. No data is presented to justify the proposed cut off point at 12 weeks, and this does not reflect patient experience. Rather this appears to be an artificial and arbitrary construct that risks impacting patient care by creating barriers to services, reviews and investigations. 10. Overall the guideline pays insufficient attention to the need for repeated investigations, and we are concerned that the guideline fails to engage adequately with the apparent relapsing-remitting nature of the condition, and the fluctuations in health reported by the majority of

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			members of our support groups. 11. While we value the holistic and multi-disciplinary approach of the guidelines, we are troubled that there is insufficient attention to the range of physical conditions experienced. We note inadequate attention to diagnosis and treatment of physical complaints, and would stress that patients need assessment, diagnosis, treatment, support and rehabilitation - not merely support and rehabilitation. 12. The research studies included/excluded are partial and biased; in particular the guideline neglects those studies indicating organ damage (for example, Puntmann et al, and Banerjee et al - Coverscan). There are a number of papers excluded which we believe merit consideration and we would argue that some papers should be excluded from consideration. 13. We detect assumptions about the nature of the condition – including through the proposed renaming as Post-Covid Syndrome - that are not borne out by any reliable or validated research. So early in the disease course we believe that it is irresponsible to presume parallels with other conditions or to make assumptions that physical manifestations of disease are due to psychological issues. 14. We are pleased to see that attention is paid to the well being and mental health of people living with Long Covid, and note that a large proportion of the population experience psychological and mental health challenges in the face of COVID restrictions. However, the guidelines appear to be seriously imbalanced and can easily be read as a belittling the lived experiences of thousands of people with persistent physical symptoms. Finally, we note that in various fora – including the NHS Long Covid Taskforce, and the Roundtables convened by PUSS Lord Bethell – members of our group have expressed concerns about some aspects of the guideline, and in particular the proposed change of name to “post Covid Syndrome”. We would respectfully request that NICE provides transparent information about the inputs received from people living with Long Covid, and other experts with lived experience, on this point of nomenclature. We are concerned that our self definition is respected, and that if this is to be altered that clear scientific evidence be advanced to explain this change in medical terminology. To date we have not seen that evidence or any compelling, well argued rationale. We are concerned that while a rapid process is required for a new and emerging condition, this process has not allowed for a balanced approach to taking the right range of evidence. We look forward to the next steps and trust that NICE will continue to listen carefully to the lived experience of thousands of previously healthy people who are now experiencing a broad range of symptoms. We appreciate the opportunity to make our contributions to the guidelines, and thank NICE, SIGN and RCGP for their meaningful engagement of people living with Long Covid. Yours sincerely, On behalf of Long Covid Support

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Neurological Alliance	Guideline	General	Overall, we feel this is a thorough document, which helps to promote many principles of good, personalised care and support. Post covid syndrome includes a number of different syndromes and likely some that we are yet to define. There are the well defined respiratory and cognitive consequences and what might be considered chronic fatigue type symptoms. With the large numbers of people who have been affected there are likely to be a large number with other disorders that develop by coincidence post covid. We saw this quite frequently in so called Gulf War syndrome. There remains the possibility that delayed neurological sequelae may occur and this possibility should be monitored - this underpins many of our suggested changes to the guideline. The guidelines emphasise the importance of clinical investigations where indicated and psychological support. The neurological disorders that are currently recognised occur in the first 4 week acute phase. These not infrequently leave the individual with persistent disability (stroke , neuropathy) that requires timely access to the rehab services that should already be available. There remains concern that there maybe delayed neurological sequelae. Members have raised concerns about the planning of long covid clinics, namely how specialist neurological input is being incorporated into these plans. We would welcome clarity on how decisions about where the clinics and service are located are being made, and proposed for delivery, bearing in mind that many referred patients will require specialist input as part of their ‘rehab’ and a significant percentage of those patients will need neurological input.
NHS England and Improvement	Guideline	General	There is no description of the methodology used to develop the guideline, for example, of research questions and protocols (including PICO framework or inclusion/exclusion criteria) or of databases searched, or of search strategies used. This should be provided in supporting documentation as part of the consultation. This is made even more important because of the ‘living guideline’ status. What will be the process for updating the ‘living guideline’? In what way is a ‘living guideline’ evidence based? Currently there is no indication of a systematic or transparent approach to identifying and summarising the available evidence to support the guideline. Can any website or reference be considered for inclusion? Why have prepublication prints been included? How will the methodology of the living guideline incorporate pre-prints being published in full (or not) subsequently? It would be helpful to have a list of existing related NICE guidance. Terms used - no description or reference is provided of what the important red flags actually are for people covered by this guideline. All that’s given is a definition of what a red flag is and that they exist and should be considered. The reader is left with more questions than answers. Please either remove mention of red flags or provide relevant description or references as to what the red flag signs/symptoms/conditions are. Included studies list: 1st page, 2nd line - What are the long-term symptoms and complications of COVID-19 - it is unclear

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			whether this is an incomplete reference or an unformatted subheader. This list does not include NHSE/I publications – should these be added?. If no description of the methodology is going to be provided for this 'living guideline' then at a minimum the included studies should be presented according to the guideline sections/recommendations that they supported. Excluded studies list: This document is meaningless without publication of the methodology used to develop the guideline as part of the consultation information, the research questions and protocols (including PICO framework and inclusion/exclusion criteria). Evidence tables: There is a field in each table "Questions relevant to?". Please publish a list of what these questions were and their corresponding research protocols. Why have pre-print publications been included in this guideline? Please explain what the process will be for updating the guideline in response to these publications.
Association of British Neurologists	Guideline	General	need to clarify who this document is intended for and who the authors are
Deaf Scotland	Guideline	General	Offer Inclusion -Communication and language access support services including BSL Interpreters, Tactile Interpreters/Guide Communicators and Electronic notetakers. Is hearing routinely assessed? Any specific strategies to support those affected by deafness/others with communication and language barriers (links to digital/technology strategies etc)? Does video service include subtitles/captioning?
Deaf Scotland	Guideline	General	Question: on average people take 4-7 years to present for hearing test/aids. Are there likely to be people affected who dismiss hearing related symptoms? Should basic tests be routine until we are clear there is no sensory impact?
Deaf Scotland	Guideline	General	We note Kevin Munro is mentioned in the included list which is helpful. Be good to know what is being done to spot hearing related changes.
Deaf Scotland	Guideline	General	Evidence Tables: It is difficult for us to say much without understanding any cross study agreement on equality and protected characteristics and ways to look at the spectrum of deafness and any Covid related hearing loss identified.
University Hospitals Coventry & Warwickshire NHS Trust	Guideline	General	This is a very comprehensive set of guidelines. I understand that NICE have reviewed the question around SARS COV 2 antibody test to determine the linkage of symptoms with Post COVID/ Long COVID syndrome and decided that it was not necessary, this would need a word of caution for referring clinicians from primary to specialist clinical services, as it may mean a lot of patients who have not had COVID 19 get referred to the specialist services for this specific need. I would have considered that suspected cases should have an antibody test and if positive this should help with the diagnosis

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			and if negative one would need to consider the other diagnostic possibilities first than Long COVID. If then the Long COVID syndrome was likely then the referral should then be made still.
University Hospitals Coventry & Warwickshire NHS Trust	Guideline	General	It is a very comprehensive set of guidelines and as it is very similar to what has been proposed I have little to add, only a few comments as listed below. I would suggest the guidance regarding rehabilitation prescription might benefit from some detail regarding what should be included (similarly to the major trauma rehab guidance) this would allow ease of use between systems and some consistency in approach. Dietetics seems to have been missed from the guidance. We have had an increased uptake from those referred from the MDT to undertake weight management - patients have seen this is a way of reducing risk and long term impacts on health and the resultant impact of COVID seems to have given them the impetus to engage. I wonder if this should be included in the guidance.
NHS England and Improvement	Guideline	General	Guideline: We recommend the guidance including more explicit detail on the importance of staff being aware of diagnostic overshadowing when managing the long-term effects of COVID-19. Staff should be aware of diagnostic overshadowing: This occurs when the symptoms of physical ill health are mistakenly either attributed to a mental health/behavioural problem or considered inherent to the person's learning disability or autism diagnosis. People with a learning disability have the same illnesses as everyone else, but the way they respond to or communicate their symptoms may be different and not obvious. Their presentation with long Covid may be different from that for people without a learning disability. We recommend the inclusion of: Speciality guidance on caring for people with a learning disability and autistic people: https://www.nice.org.uk/Media/Default/About/COVID-19/Specialty-guides/learning-disability-autism-during-pandemic.pdf We recommend the guidance should include more explicit reference to understanding behavioural responses to illness/pain/discomfort: A person with a learning disability and some people with autism may not be able to articulate their response to pain in the expected way: eg they may say that they have a pain in their stomach when the pain is not there; may say the pain is less acute than you would anticipate; or not say they are in pain when they are. Some may feel pain in a different way or respond to it differently: eg by displaying challenging behaviour; laughing or crying; trying to hurt themselves; or equally may become withdrawn or quiet. People who use a wheelchair may have chronic pain. Understanding what is 'normal' for that person by talking to them, their family and carers, is crucial to helping with assessment and diagnosis. You can use pictures to help establish whether a person is in pain and where that pain is. Some people with a learning disability and some people with autism may have a healthcare passport giving information about the person and their health needs, preferred method of communication and other preferences. Ask the person and/or their accompanying carer if

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			they have one of these. EIA: We recommend there is more detail in the EIA about reasonable adjustments. We recommend it includes reasonable adjustments being a legal requirement and is important to help you make the right assessment decisions for an individual. You can ask the person and their carer/family member what reasonable adjustments should be made. Adjustments aim to remove barriers, to do things in a different way, as well as to provide something additional to enable a person to receive the assessment and treatment they need. Examples include: allocating a clinician by gender, taking blood samples by thumb prick rather than needle, providing a quiet space to see the patient away from excess noise and activity. We recommend the EIA includes more detail on the importance of communicating with and understanding the person you are caring for. It is important, staff check with the person themselves, their family member/carer or their hospital/communication passport for the best way to achieve this. Use simple, clear language, avoiding medical terms and 'jargon' wherever possible. Some people may be non-verbal and unable to tell you how they feel. Pictures may be a useful way of communicating with some people, but not all.
National Voices	Guideline	General	You recognise yourself that the deadline to provide feedback is very tight. We appreciate that it is better to have some guidelines in place than none, but we do think it is necessary to keep reviewing the guidelines in light of emerging evidence, and also to keep engaging with patients and their organisations in light of the rushed timeline for publishing this first guideline. As a coalition of 170 healthcare charities and organisations, National Voices are happy to help with this engagement. We have a strong track record of putting on successful engagement events with the wider sector but can also workshop some of your emerging questions with a smaller number of trusted colleagues from a range of member charities. Please do reach out if you would find this helpful. Thank you for sharing your draft guideline with us. Please do take up our offers to help, both with wider engagement and equalities issues. We are also very happy to have a further conversation if you would find that useful.
Chronic Long Covid	Guideline	General	we welcome the balanced clinical / psychological approach , this has been a fundamental issue for some of our patients in these initial stages
POTS UK	Guideline	General	We would only add that if recommendations are made to direct patients to support groups that these be reliable, run by HCPs, social media moderated and recommended by reliable monitoring bodies such as government or the NHS.
Royal College of Physicians	Guideline	General	We endorse the response submitted by the British Thoracic Society (BTS).

Managing the long-term effects of COVID-19
Targeted consultation on draft guideline
Comments table
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Scottish Intercollegiate Guidelines Network (SIGN) Council	Guideline	General	There was no recommendation whether a positive or a negative Covid test itself should be coded. Was there a lack of evidence regarding this? Or was there not enough evidence to support this? It would make sense for the other recommendations e.g. investigation of risk factors that covid test results are coded in the patient notes to allow follow up for clinical reasons, but also to support future research, be it clinical or be on a population level to estimate the burden of disease and a need for future service delivery.
National Institute for Health Research, Centre for Engagement and Dissemination	Guideline	Rec 1.1	Information should be given in public health messaging, so that those without a positive test are aware of the possibility of ongoing symptoms
Royal College of Occupational Therapists	Guideline	Rec 1.1	line 6: suggest "what to expect during their recovery, and advice on how to self-manage during recovery e.g. www.yourcovidrecovery.nhs.uk"
Forth Valley Public Patient Partnership	Guideline	Rec 1.1	1.1 Gives information clearly about what to look out for in identifying symptoms It defines 3 phases following infection.It also provides timescales with clear information on recovery
NICE GP Reference Panel	Guideline	Rec 1.1	The patient should seek medical advice if concerned e.g worsening breathlessness, unexplained chest pains, SpO2
Faculty of Health Sciences, Oxford Brookes University	Guideline	Rec 1.1	This is not well written. Does it mean that the person has to have had previous contact with healthcare services in order to be given this advice, or does it mean giving it to someone when they first contact healthcare services about problems that might be due to acute infection? It is not clear whether you are requiring people to have had a previously confirmed diagnosis of actual or possible infection, whether you are simply meaning that someone who states that they have had an infection should be given this information. What it should say is that anyone who attends at any time stating that they have had or think that they have had infection should be given advice and written information as stated. This is a

Stakeholder	Document	Section	Comments
			key statement, and must be much clearer than it is at present. It should not require that someone has been seen prior to this consultation. Indeed it does not state at what point after the infection this statement becomes active.
The ME Association	Guideline	Rec 1.1	As there appears to be no opportunity or space to provide general comments on the guideline, and what we (the ME Association) regard as significant omissions, I am going to enter this here: GENERAL It is surprising and disappointing to find that the draft guideline: (1) Has no recognition that some of the common underlying clusters of symptoms being reported in people with Long/Post COVID are exactly the same as those found in people with a post viral fatigue syndrome (PVFS) or ME/CFS The key overlapping symptoms include activity-induced fatigue; myalgia; cognitive dysfunction/'brain fog'; dysautonomia - involving orthostatic intolerance, postural orthostatic tachycardia, postural hypotension; headache; problems with thermoregulation unrefreshing sleep patterns and post exertional malaise/symptom exacerbation. It would be very surprising if this was not the case given the fact that any type of viral infection can trigger a post viral fatigue syndrome and research carried out following previous coronavirus infections has reported that 10% or more of those infected go on to develop a PVFS or an ME/CFS like illness. (2) Contains almost no information on the pragmatic management of the symptoms that are being commonly reported - activity and energy management in particular. This is also very surprising when a new draft guidance from NICE on the management of ME/CFS has just been published for stakeholder consultation. This guidance contains detailed recommendations on the sort of energy and activity management that is applicable to people with a post viral fatigue syndrome (regardless of triggering infection) and ME/CFS in both the pre diagnosis and post diagnosis stages. Link to draft guideline: https://www.nice.org.uk/guidance/GID-NG10091/documents/draft-guideline It should not be left to the charity sector to be providing the sort of detailed self help management guidance on all these common symptoms that people with Long COVID are reporting. MEA guidance on post COVID fatigue and Long/Post COVID syndromes: https://meassociation.org.uk/wp-content/uploads/Post-Covid-Fatigue-Syndrome-and-MECFS-September-2020.pdf OMISSIONS: EPIDEMIOLOGY AND DEMOGRAPHICS Whilst acknowledging that evidence is preliminary and emerging there should be more information on what we currently know about the epidemiology and demographics of COVID. In particular: Most cases are being reported in people who self managed at home with a mild or moderate illness Many are previously fit young adults in their 20s to 50s Cases being reported in children and adolescents as well Female predominance Current evidence suggests that around 10% of people who develop COVID are developing prolonged symptoms - there could be up to 60,000 people with Long COVID DIET AND NUTRITION Why is there no guidance on diet and

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			nutrition, especially strategies that can help to sustain energy requirements throughout the day and encouraging good fluid intake - which can help with orthostatic intolerance
Polymyalgia Rheumatica and Giant Cell Arteritis Scotland (PMR-GCA Scotland)	Guideline	Rec 1.1	Strongly support the requirement to do this but "information about the availability of information" must be available both to those who may require it and their carers, to include those who are not yet in the system. This would require open advertising and public information on eg roadside hoardings and in supermarkets for those who are out and about and also on Twitter and Facebook for those who do not access any other kind of information content.
Chartered Society of Physiotherapy	Guideline	Rec 1.1	1.1 Further information provided on symptoms and recovery expectations is required, seems contradictory to the lack of evidence at present. What should be said /not said?
ICUsteps Peer Support Charity	Guideline	Rec 1.1	1.1 'symptoms to look out for that mean they need to be reassessed' – clarify what is meant here as the reader may misinterpret. Meaning that it may be another condition? Or reassessed from what (from long covid diagnosis)?
Long Covid Wales	Guideline	Rec 1.1	In general regarding section 1, unless covered in detail elsewhere (as commented on in notes to line 15 in 'terms of use in the guideline' under general comments), a detailed list of possible signs and symptoms of COVID-19 as well as Long COVID needs to be included. It should also include a comment noting that this list is not exhaustive owing to the developing nature of this illness. Regarding 1.1, considering Long COVID is a complex multi-system illness, a list of symptoms to look out for that would indicate the need for reassessment may not be feasible. Instead, highlighting that any new or worsening of existing symptoms would trigger a review may be more appropriate.
British Society of Rehabilitation Medicine (BSRM)	Guideline	Rec 1.1	Many in the first wave did not have contact with health services, were symptomatic & were actively advised not to increase NHS workload. Some of these affected individuals may still not be in contact with health services or may not realise that ongoing difficulties could be due to the consequences of COVID-19. This group could include the elderly, patients with cognitive impairments from varying causes, people who are homeless, those who are in England without legal status to remain (so do not have an NHS number). There is concern that these patients may again fall through gaps of healthcare provision. How will these patients be identified?
UEA/Fifth Sense/The	Guideline	Rec 1.1	Advice can be found at www.fifthsense.org.uk for self-assessment of smell/taste in the first instance

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Norfolk Smell and Taste Clinic			
Patient-Led Research for COVID-19	Guideline	Rec 1.1	After line 10, we recommend including resources on the importance of rest and pacing during recovery such as this resource from the Royal College of Occupational Therapy: https://www.rcot.co.uk/file/6696/download?token=XiA9qFCs.
British Geriatric Society	Guideline	Rec 1.1	As there is no commitment in the guidance as to which healthcare service should be responsible for giving this advice, there is a risk that one service would think it the role of the other. At present, if a patient has been discharged after covid infection, in my experience as a GP there is generally no advice on the discharge letter for the GP to follow up the patient as this occurs within the hospital outpatient setting. It would be helpful to know whether there is standardised information being given to patients on discharge from hospital after covid infection- are they all advised to use the "your covid recovery" website? It would also be helpful to have a link to the " your covid recovery" website in this first paragraph (for the busy clinician as well as patient/ carer) when referring to the bullet points about what to expect/ symptoms needing review etc. I think there should be more emphasis on the difficulty of identifying a past case of atypical covid, particularly in the case of older patients who may not have presented to healthcare professionals with atypical symptoms. Until the public health campaign makes it clearer that older patients can present with atypical symptoms, the public will not suspect this as a possibility or request testing for such symptoms. They may be less likely to link these symptoms to a possible covid infection and may not report the episode acutely or subsequently. Even if advised by a GP, patients would have to lie on the 111 website in order to fulfil the testing criteria, and there is no way of testing such patients in the community if they cannot do the test themselves and are not assessed in hospital. GPs have been told not to examine throats due to aerosol generation and community nurses/ professional carers do not conduct the tests in the home. In determining ongoing covid infection in frailty, all these points make it very difficult for a GP to know whether covid should be included in the differential. Given that GPs cannot request antibody tests in the community, plus the controversy over their reliability, the ability of GPs to differentiate ongoing covid symptoms from other potential causes of fatigue and breathlessness in the absence of typical symptoms will be very difficult in the presence of polypharmacy and multimorbidity. Many older patients, carers and GPs may underdiagnose ongoing covid if the patient had pre-existing frailty and is thought to have deteriorated as a result of deconditioning in lockdown, for example. Regarding timeframes, if ongoing covid is a possibility, often patients underestimate the length of time since the onset of vague symptoms or the

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			acute atypical episode, particularly if they have cognitive impairment or no fixed date to remember the onset, such as when they first requested sick notes. This is likely to pose a challenge in determining the 12 week watershed.
The Royal College of Pathologists	Guideline	Rec 1.1	A/ Section 1.1: Why only include those who have accessed healthcare? Some who test positive will not access healthcare formally. Everyone who tests positive should be sent the relevant information about recovery etc. even if they do not contact formal healthcare services. 1/ There seems to be a missing question mark on Page 13 under the section 'Key recommendations for research'. 2/ Line 5 (page 13) - seems to need a question mark after the risk of developing post-COVID-19 syndrome'?'
Patient Safety Learning	Guideline	Rec 1.1	We believe that this must include information to people living with Long COVID on what the signs and symptoms of this are. Communications to people living with Long COVID should be clear and accessible. Information should be available in different formats, languages, jargon-free and in line with the NHS information standards. There also needs to be a proactive and publicly visible communication plan to make sure patients are aware of what information exists and know how to access it, which needs to be rolled out in an inclusive and accessible way. The meaning of Line 7 is unclear. When would people living with Long COVID need to be re-assessed? There is a need to explain whether this refers to additional symptoms, an escalation of patient concerns etc. It also should be made clear who should be making this determination: just patients and primary care physicians; Long COVID clinics; secondary care clinicians?
Public Health Scotland	Guideline	Rec 1.1	Those who did not contact healthcare services are exempt here? – Why? Perhaps an online resource where these people can access this information would be important – in the first wave most people were not tested (was not available) and told to stay away from healthcare services
The Society and College of Radiographers	Guideline	Rec 1.1	P3 Line 1 Does this exclude a person who who did not seek medical advice during their illness but displays ongoing symptoms of COVID-19?
Science for ME	Guideline	Rec 1.1	1.0 Rename Section 1: 'Identifying people with new or ongoing symptoms after acute Covid-19' (rather than the current 'Identifying people with ongoing symptomatic COVID-19 or post-COVID-19 syndrome'. This is because you cannot identify people with anything specific until the assessment is done, which is covered in Section 2. 1.1 There needs to be more guidance on what information is to be provided to people, perhaps by means of links. The information should be evidence based. Information relating to post-viral syndrome/ ME/CFS should be based on the new draft NICE ME/CFS Guideline and/or information from major national ME/CFS charities.

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ME Action UK	Guideline	Rec 1.1	There should be clear acknowledgement that for those with ongoing symptoms, prognosis is currently unknown. Health professionals cannot advise on what patients can expect in their recovery if there isn't evidence on this.
British Thoracic Society	Guideline	Rec 1.1	Identifying the right individuals will be key, so clarification on what constitutes 'suspected' acute COVID-19 is necessary to exclude people with general post-viral fatigue or lockdown-induced psychological morbidity. For example, in the absence of a positive PCR test, compatible symptoms plus a chest X-ray showing lung changes consistent with acute COVID.
Royal College of Nursing	Guideline	Rec 1.1	General – the draft guidance is structured well and a much-needed rapid guidance. Section 1 – Need to make reasonable adjustments where necessary such as for people with learning disabilities, mental health problems and those with English as a second Language etc.
Public Health England	Guideline	Rec 1.1	Line 12, P2 – I would like a more scientific definition to be used throughout as per the title 'long-term effects of COVID-19' rather than 'long COVID' which is throughout the text; it is fine to mention how it is colloquially mentioned here but I would avoid elsewhere in the text Line 7, P3 – 'what to expect during their recovery', this should be accompanied by a list of likely symptoms/timelines for resolution for people to have this conversation consistently or links to the 'relevant national guidance' mentioned in Lines 14-15 Line 9-10, P4 – How should people proactively follow up those who have self-isolated without a test, they would largely be unaware of their existence
British Psychological Society	Guideline	Rec 1.1	The BPS welcomes 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. 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 et al 2014) 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. 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

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			have a) received this information and b) ask them to explain their understanding of the information they received. Refs: Ley, P., 1997. Communicating with patients: improving communication, satisfaction and compliance. Cheltenham: Thornes. Reuben A, Sampson P, Harris AR, et al (2014) Post-concussion syndrome (PCS) in the emergency department: predicting and pre-empting persistent symptoms following a mild traumatic brain injury. Emergency Medicine Journal, 31, 72-77.
Scottish Intercollegiate Guidelines Network (SIGN) Council	Guideline	Rec 1.1	Bullet 1 - Is this written information available? If so, it might be useful to state resources that can be used.
Clinical Advisors to the Scottish Government (Clinical Guidance Cell, Professional Advisory Group)	Guideline	Rec 1.1	This section is the most important part of what is largely a non-evidence based guideline. I would expect an example of this with the text here. Appropriate, fits with RM, written information will not suit everyone .Make sure it is consistent and available via range of routes but signposting to one route where material is curated and maintained essential.
Long Covid Support Group	Guideline	Rec 1.1	Line 3: Why only people who had contact with healthcare services? Information should also be made available online, notably on NHS websites. Lines 7-8: Refine wording to recognise that existing symptoms can worsen.
Neurological Alliance	Guideline	Rec 1.1	Overall, the guideline emphasises shared decision-making, information provision, a point of contact for care and care coordination throughout – this is hugely welcomed, and form the basis of good, personalised support.
Royal College of Speech and Language Therapists (RCSLT)	Guideline	Rec 1.1	As it is not currently included on this draft, we suggest external stakeholders will be listed on final draft (so RCSLT will be mentioned) to add further weight for SLT inclusions Red flags: we suggest adding that 'this requires assessment and referral from a trained healthcare professional to rule out other serious complications'. We also suggest including some guidance around defining the red flags and distinguishing from covid?

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National Voices	Guideline	Rec 1.1	Terminology: We are aware that there seems to be a preference for Long Covid – as opposed to post-Covid syndrome or the like amongst people who have experience of living with ongoing Covid symptoms. We think we should use this label since it seems to resonate with their experience of this being an ongoing problem without implying that it will be chronic or that one phase necessarily always follows another. We think it is one of the examples where privileging the lived experience of people over the absence of firm professional knowledge or consensus makes sense.
National Institute for Health Research, Centre for Engagement and Dissemination	Guideline	Rec 1.2	Ensure that easy read versions are availble for people with Learning Disabilities
Royal College of Occupational Therapists	Guideline	Rec 1.2	suggest additional point – “raising awareness of resources to support self-management of symptoms and recovery, e.g. www.yourcovidrecovery.nhs.uk”
Forth Valley Patient Public Partnership	Guideline	Rec 1.2	Equality Impact document backs up the need for this with the need to tailor support information to different age groups particularly the elderly and young which the guideline addresses but perhaps the specific needs of the disabled,those with sensory impairment,autism,communication impairment such as poor eyesight,hearing and learning difficulties.Also needs of migrant groups,asylum seekers and refugees Perhaps a Patient Version could address these issues and be produced in different formats
Faculty of Health Sciences, Oxford Brookes University	Guideline	Rec 1.2	None
Polymyalgia Rheumatica	Guideline	Rec 1.2	See above

Stakeholder	Document	Section	Comments
and Giant Cell Arteritis Scotland (PMR-GCA Scotland)			
Asthma UK/British Lung Foundation	Guideline	Rec 1.2	Given the disproportionate impact of Covid19 on the BAME community, we would urge the health services to ensure information is available in a wide range of languages and that interpreters are available where necessary.
ICUsteps Peer Support Charity	Guideline	Rec 1.2	There are a number of sources of information provided by charities such as ICUsteps that provide downloadable patient and healthcare professional written information for post ICU patients in a number of languages and post Covid at https://icusteps.org/home/covid-19.
Long Covid Wales	Guideline	Rec 1.2	“Accessible formats” should take into account the fatigue, lethargy, malaise and brain fog associated with Long COVID, as well as addressing the known differences in presenting to and accessing healthcare in e.g. men and those of BAME background.
Patient Safety Learning	Guideline	Rec 1.2	It is not clear from the guidance who will be responsible for this. The NHS information standard needs to be clearly referenced if this is the ‘relevant national guidance’ being referred to here.
British Psychological Society	Guideline	Rec 1.2	The BPS agrees that providing information in accessible formats is crucial. 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. 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. 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.
Clinical Advisors to the Scottish Government (Clinical	Guideline	Rec 1.2	It should reference the “relevant national guidance”. Agree. Create content those who do not have English as a first language, reading difficulties. Should be available in audio, braille and translated format.

Stakeholder	Document	Section	Comments
Guidance Cell, Professional Advisory Group)			
Royal College of Speech and Language Therapists (RCSLT)	Guideline	Rec 1.2	We recommend explicitly referencing the shared decision making guideline and other relevant guidelines which support patient experience. Accessible formats need to include aphasia friendly format.
National Voices	Guideline	Rec 1.2	We support the focus on information giving and the need for accessibility. We think it would be good to highlight even at this stage the value many people find in peer support, and the emerging nature of professional knowledge. It would also be great if people could signposted to sources of support and to options for taking part in research or service design and improvement at the point of diagnosis. We have recently commissioned work on the rollout of social prescribing which will be useful: https://www.nationalvoices.org.uk/our-work/SocialPrescribing
Engender	Guideline	Rec 1.3	It is important to demonstrate cognisance of gender discrepancies in clinical diagnosis. A significant body of sex and gender medical research shows that women are more likely to receive psychological diagnosis reporting the same physical symptoms as men, to receive a generalised anxiety or stress diagnosis that follows them from clinician to clinician or to be labeled difficult. Given the degree of unknowns in long-covid - from symptoms to scale - the risk of misdiagnosis is significant, and the guidance should proactively engage with known gendered biases.
Forth Valley Patient Public Partnership	Guideline	Rec 1.3	Timescale given and possibility for treatment of Long Covid Issues like overlapping symptoms considered(p18)
Faculty of Health Sciences, Oxford Brookes University	Guideline	Rec 1.3	This shows a logical inconsistency. In this statement and in the definition of post Covid syndrome there is a severe ambiguity. It can be considered and therefore presumably diagnosed between four and 12 weeks and yet it is also implied that it cannot be diagnosed before 12 weeks. Given that there is no magic about 12 weeks – why not 11 or 13, why not four or 16 – and given that it is to be considered at any time after four weeks, the statements are simply muddling everybody. It would be much more clear and less liable to misinterpretation if you just stated that the syndrome can be considered, and therefore diagnosed, any time after four weeks. Until there is some rational, evidence-based method of

Stakeholder	Document	Section	Comments
			distinguishing ongoing symptoms from a syndrome, it seems pointless, positively muddling and possibly harmful to impose arbitrary time limits.
NICE GP Reference Panel	Guideline	Rec 1.3	this was difficult to read and understand, it reads like a definition of on-going covid and long covid. People will present with diffuse symptoms that may or may not be COVID-related. could the emphasis be changed, e.g. Think about the possibility of COVID-related illness when considering the underlying cause of new or on-going symptoms . this may be - ongoing symptomatic COVID-19 - post COVID-19 syndrome in people who have new or ongoing symptoms 4 to 12 weeks after the start of confirmed or suspected COVID-19. - In people whose symptoms have not resolved by 12 weeks, think about the possibility of post-COVID-19 syndrome
Patient Advisory Group to the CFS/ME Research Collaborative (CMRC)	Guideline	Rec 1.3	It is unclear how post-COVID-19 patients who meet the diagnostic criteria for ME/CFS, and who do not have additional symptoms that are not part of the symptom of ME/CFS, differ from ME/CFS patients who in the majority of cases develop symptoms after viral illness.
Chartered Society of Physiotherapy	Guideline	Rec 1.3	How to differentiate in the definitions for those that have an elongated recovery due to severity of infection (e.g. post ITU or organ damage), vs those that have long term / fluctuating symptoms following COVID-19 infection.
Long Covid Wales	Guideline	Rec 1.3	As touched upon in comments to the introduction (under general comments), this also needs to cover those with asymptomatic COVID-19 infections, or such mild infections that a diagnosis of COVID-19 is not considered, who later go on to develop Long COVID as well as those who recover but at a later stage relapse and develop Long COVID.
British Society of Rehabilitation Medicine (BSRM)	Guideline	Rec 1.3	This recommendation should be more robust, given it is at the beginning of this guidance. Consideration should be given, however it is looking increasingly that post-COVID syndrome is a diagnosis of exclusion so other potential causes should also be considered. We suggest adjusting the wording to “consideration should be given to ….. if patients present with symptoms & signs consistent with post-COVD syndrome” We are unclear why 4 weeks & 12 weeks have been chosen as timelines. Are symptoms at 4 weeks likely to still be persistent at 12 weeks? Do new symptoms present at 12 weeks, or do patients present at 12 weeks?

Stakeholder	Document	Section	Comments
The Royal College of Obstetricians & Gynaecologists	Guideline	Rec 1.3	Lines 16-17. Suggest remove 'or post-COVID-19 syndrome' from here as this sentence refers to 4-12 weeks; the next sentence is for symptomatic people beyond 12 weeks.
UEA/Fifth Sense/The Norfolk Smell and Taste Clinic	Guideline	Rec 1.3	Advice can be found at www.fifthsense.org.uk on the symptoms that can arise in relation to smell and taste
British Geriatric Society	Guideline	Rec 1.3	The term "new or ongoing symptoms" needs clarification for clinician and patients - does it mean the symptoms on "your covid recovery" website, or any symptoms affecting any part of the body? If someone was asymptomatic with a positive swab initially, do any new symptoms over the next 3 months potentially have to be regarded as possibly covid-related?
Patient Safety Learning	Guideline	Rec 1.3	Who is this directed to? If this guidance is directed to GPs, then this should be stated. As currently written we feel this would be unclear to both clinicians and patients.
Science for ME	Guideline	Rec 1.3	1.3 Reword to 'If a person has new or ongoing symptoms 4 to 12 weeks after the start of confirmed or suspected COVID-19, consider ongoing symptomatic Covid-19, post-Covid-19 tissue damage, or post-Covid ME/CFS. If the person meets the criteria for ME/CFS in the 4 to 12 week period other than the time-requirement, advise the person to monitor activity and symptom patterns and to take a cautious approach when returning to pre-illness activities.'
BAME Health Collaborative (BHC)	Guideline	Rec 1.3	1.3. The definitions of ongoing symptomatic COVID-19 and post COVID-19 syndrome are best on symptoms 4 – 12 weeks after the start of confirmed or suspected COVID-19. This timing needs clarification to the readers, how is this start point defined.
National Guideline Centre	Guideline	Rec 1.3	The section on the three phases (page 2, lines 13 to 21) and recommendation 1.3 (page 3 lines 16-20) have compatibility with the ME/CFS guidance and the times to suspect and diagnose ME/CFS but it demonstrates the potential for confusion between ME/CFS and post-COVID-19 syndrome and the difficulty in diagnosing which is which.

Stakeholder	Document	Section	Comments
British Psychological Society	Guideline	Rec 1.3	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.
Scottish Intercollegiate Guidelines Network (SIGN) Council	Guideline	Rec 1.3	In section 1.3 I think it should define what the evidence suggests the new or ongoing symptoms of COVID actually are and include the incidence of commonly reported side effects. There is reference to common symptoms such as in section 5.5 of the guideline "symptom management for all presenting symptoms, for example advice and education on managing breathlessness, fatigue and brain fog". However, there are other common symptoms that are in the evidence table but are not referred to in the guideline, such as sleep disturbance and pain: Arnold 2020: insomnia Bicruz 2020: sleep disturbance and pain Daher 2020: Headache, myalgia, sore throat Dennis 2020: Muscle ache, headache, joint pain, sore throat Savaray 2020: pain Valiente De Santis 2020: Headache Zhao 2020: headache Andrenelli 2020: sleeping problems and pain Landi 2020: Headache, joint pain, sore throat These symptoms will be self managed in the community and sources of advice for patients will be from Community Pharmacy, especially when managing pain.
Clinical Advisors to the Scottish Government (Clinical Guidance Cell, Professional Advisory Group)	Guideline	Rec 1.3	“think about” This language is not helpful. The general tone of the writing is along the lines of a teaching exercise. It should be statements of fact. Necessary given the impact of symptoms.
Long Covid Support Group	Guideline	Rec 1.3	What exact symptoms before 12 weeks should prompt calling it ‘post-Covid-19 syndrome’? What exact symptoms after 12 weeks signal the ‘diagnosis’ of post-Covid-19 syndrome? It is important that access to care is not limited by the officially recognised symptoms. Given the diversity of presentations of Covid-19, this infection should be always be suspected at the current time.
Association of British Neurologists	Guideline	Rec 1.3	approve of the attempt to define more clearly different phases of infection and avoid ‘long COVID’. The use of post-COVID19 syndrome is preferable and aligns better with similar syndromes • there is lots of emphasis on “long COVID” – sense is that it is important to treat people on the basis of their symptoms

Stakeholder	Document	Section	Comments
			(which are seen in many other settings) but also to ascertain who actually had covid to inform future provision of care and differentiate disease specific from generic mechanisms
Engender	Guideline	Rec 1.4	It is important to maintain flexible appointment times. Women may benefit from video or remote appointments which reduce travel time or other barriers where they have other care responsibilities or the cost - both in time and resource of attending. However, other women may depend on in person interaction, for example some disabled women, women who need additional privacy that cannot be guaranteed in the home and women experiencing domestic abuse. Women's lesser access to digital devices and skills, particularly poorer women, older women and disabled women must be considered.
Forth Valley Patient Public Partnership	Guideline	Rec 1.4	Precedent of “Near Me “ Consultations might well be incorporated in recommendations
Faculty of Health Sciences, Oxford Brookes University	Guideline	Rec 1.4	This suggests using a screening questionnaire, but 1.5 suggest that a screening questionnaire is not valid. This is contradictory and muddling. It is not useful guidance. It could say "use of a screening questionnaire may help in eliciting other symptoms, but it should not be used as the only criterion for making a diagnosis."
Cardiff and Vale UHB	Guideline	Rec 1.4	would be useful to say which screening tools you are recommending, is it the ones mentioned later e Yorkshire? if so please sate here for its clearer yes agree non face to face the best initial consultation
GP	Guideline	Rec 1.4	This implies we proactively contact people which is not likely to be realistic. It risks labelling/ medicalising recovery.
Carers Scotland	Guideline	Rec 1.4	The guideline should recommend that there is an opportunity for a carer or family member to be involved in such initial discussions, particularly where the individual has a sensory impairment or learning disability. The guideline should recommend that the practitioner should consider as part of their initial actions where it is may be more appropriate and effective that an initial appointment is face to face. The guideline should also recommend that the practitioner consider from the outset ascertaining if and what additional communication support may be needed and should arrange for this to be in place. This may be translation services, advocacy, or it may be support from family who know and understand a person's more complex communication including non verbal.

Stakeholder	Document	Section	Comments
UK Doctors Long COVID Group	Guideline	Rec 1.4	How would patients who didn't access healthcare during their acute COVID illness be identified? o Will test and trace notify GPs of positive test results for their patients? ? If yes will GPs be expected to contact all patients with a positive test after 4 weeks to conduct the screening questionnaire? ? If no it should be highlighted that all patients contacting their GP who reference a COVID infection in the past few months should be screened with the Post-COVID syndrome screening questionnaire or be offered a further appointment for the screening questionnaire to be conducted
British Society for Rheumatology	Guideline	Rec 1.4	We presume that the offer of a telephone or video consultation would be made by the patient's GP – clarity is needed with regards to this recommendation as to how positive patients will be "flagged" to their GP as GPs are not informed of all positive results
Royal College of Physicians and Surgeons of Glasgow	Guideline	Rec 1.4	One of our reviewers was concerned that a face to face consultation is missing from this initial consultation, face to face may be necessary. This should be part of the initial contact particularly if the individual is past the infectious stage of the disease. It is recognised that this is part of the plan further down the guideline. Other forms of consultation may exclude some members of society as stated.
Chartered Society of Physiotherapy	Guideline	Rec 1.4	How will case identification occur? Where are they presenting to? How do we prevent digital or social inequality impacting on someone's access to this? What if they do not have a phone or the internet?
ICUsteps Peer Support Charity	Guideline	Rec 1.4	Who is offering the consultation and how will they identify the people are with new or ongoing symptoms. If these are ICU admissions for Covid they are easy to identify at discharge but a GP may have no idea who in their practice has had a positive Covid test! The link to the rationale for how to identify appropriate patients is not apparent until P4 after section 1.8. I would contemplate moving the link to behind section 1.4 or number the links so they can be referred to earlier in the document.
Royal College of General Practice England, Wales, Scotland and Ireland	Guideline	Rec 1.4	Can the committee consider clarifying the purpose of the telephone call? Is this a proactive follow up? If so, this will increase workload significantly and is not viable. It is General Practice who will be responsible for these calls and due to workforce issues will not be achievable. Consider a change to "for patients who are concerned about ongoing symptoms, 4 weeks or more after acute covid-19, offer an initial remote consultation (telephone or video)
Long Covid Wales	Guideline	Rec 1.4	Telephone or video may be difficult for those suffering from long COVID, hence our suggestion for e.g. 1-on-1 consultations and home visits.

Stakeholder	Document	Section	Comments
British Society of Rehabilitation Medicine (BSRM)	Guideline	Rec 1.4	It is important that a structured assessment approach is used because patients may not volunteer symptoms/difficulties & may not recognise any difficulties they have as potentially being a post COVID consequence, or potentially serious eg: stridor in patients who have had tracheostomy in the acute phase where there is a risk of tracheomalacia or other post tracheostomy complications. Equally they may attribute symptoms of another illness to post COVID, so result in diagnostic delays. Screening questionnaires provide structure & ensure that all potential aspects of post COVID presentations are queried.
The Royal College of Obstetricians & Gynaecologists	Guideline	Rec 1.4	Lines 21-23. I am not clear if the guideline is recommending that everyone who has had confirmed or suspected COVID infection should receive a telephone or video consultation – this would be an arduous undertaking for primary care.
British Geriatric Society	Guideline	Rec 1.4	Having read the rationale I understand the reluctance to suggest a non-validated screening questionnaire, but until this is available should it be suggested at all? It is likely that many older people would agree with symptoms such as muscle aches and fatigue, especially if taking statins or deconditioned from lockdown. Point 1.5 states not to rely on the screening questionnaire, and screening implies false positive and false negatives.
Public Health Scotland	Guideline	Rec 1.4	Which professional group is this aimed at – primary or secondary care or both, and which specialities – will this be all specialties, or be targeted at a few?
The Society and College of Radiographers	Guideline	Rec 1.4	P3 line 23 Is there a specific screening questionnaire that is recommended or a number of examples?
UK Faculty of Public Health	Guideline	Rec 1.4	Page 3 line 23 Screening tools. The guidance expands on the challenges of this (page 16 line 13 and page 17 under 'further investigations') . We recognise that at local level one of the greatest challenges will be triaging patients to identify those who are most likely to have a post-covid' syndrome, and manage or signpost effectively from primary and community care. We strongly support the guidance research recommendation on Validated tools for screening (page 14 line 11) but would consider this was a urgent early priority to avoid the risk of more specialist services being inappropriately overwhelmed.

Stakeholder	Document	Section	Comments
National Guideline Centre	Guideline	Rec 1.4	Page 3, line 23. We are not aware of a validated screening questionnaire in post-COVID-19 syndrome, although some (such as the C19-YRS tool) are in use. If a screening tool is used, this should be as part of a clinical trial of its utility in this population. Screening tools should not be imported in to use in post-COVID-19 syndrome from other areas such as ME/CFS without validation in people with the post-COVID-19 syndrome. It is important for initial screening of self-reported symptoms to be followed up by subsequent clinical examination in order to identify other disorders. We note there is a research recommendation on screening tools.
Co Durham CCG	Guideline	Rec 1.4	We agree with this in principle, but areas where infection rates are high are usually those with greatest deprivation and poorest resources already. This is a significant burden on those health services and whilst NICE are not responsible for 'delivery' we do think this should be considered before the guideline is published.
Clinical Effectiveness Southwark	Guideline	Rec 1.4	this is a little unclear. Should we be offering a consultation in order to identify people with ongoing symptoms (i.e. all patient who had Covid would be asked to call). Or can we offer a consultation just to those who do have ongoing symptoms? If all Covid or suspected Covid patients are to be spoken to , this will be a major piece of work so I feel the guidance should be tighter to avoid confusion. In southwark for instance we are proposing to text all paitent who had covid or suspected covid asking them to call their GP IF they have ongoing symptoms. Is this what the guidance is suggesting should happen?
British Thoracic Society	Guideline	Rec 1.4	An example of a suitable questionnaire could appear in the text rather than later on in the appendix.
Department of Health (Northern Ireland)	Guideline	Rec 1.4	The wording used in the guideline is very important as once issued, it will become an obligation on commissioners and providers. As an example, in para 1.4 it states ‘Offer a telephone or video consultation to identify people with new or ongoing symptoms….’. This could imply an obligation on someone (in primary or secondary care) to case find. There are many hundreds of thousands of people who will have had Covid-19 with it being very resource intensive to contact all those with positive tests. Although this might not be the intention, it needs to be clarified and the wording changed if instead it was intended to read that only patients who contact GPs with symptoms suggestive of ongoing or post-Covid symptoms are to be offered phone/video advice in the first instance.

Stakeholder	Document	Section	Comments
British Psychological Society	Guideline	Rec 1.4	The BPS generally welcomes proactive screening, 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). 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…” 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. 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.
Scottish Intercollegiate Guidelines Network (SIGN) Council	Guideline	Rec 1.4	Final sentence - This sentence should be at the beginning of the next paragraph 1.5 and not at the end of this paragraph as there is insufficient evidence and there is not validated screening questionnaire.
Clinical Advisors to the Scottish Government (Clinical Guidance Cell, Professional Advisory Group)	Guideline	Rec 1.4	Not clear who should do this or what the patient pathway looks like. The screening questionnaire should be defined/referenced and evidence based if it is mentioned. Why say this could include a screening questionnaire if in recommendation 1.5 say that you should not rely on them? This will only be appropriate for some people. From evidence-needs to be a multidisciplinary assessment via telephone(Spruit) Assessment needs to include physical examination (Greenhaulgh a).This is not amendable to a telephone assessment In pt reported study (Xiong 2020) patients reported 32 symptoms and this is unrealistic to assess in a time limited telephone assessment. Some studies referend using 6 questionnaires to assess a range of potential multiorgan impacts. This is not realistic on a single telephone consultation and indeed if it were it would need significant multidisciplinary expertise to perform in order to get a full understanding of severity and impact.

Stakeholder	Document	Section	Comments
Long Covid Support Group	Guideline	Rec 1.4	Why specify phone or video appointments and exclude face-to-face? Suggest removing reference to the type of appointment and leaving this to the discretion of the practitioner, taking into account patient preference.
Neurological Alliance	Guideline	Rec 1.4	Increasingly, evidence suggests cognitive deficit amongst people who no longer experience symptoms of COVID-19. Given the prevalence and possible severity of cognitive deficit amongst people with post-COVID-19 syndrome, conducting a telephone based cognitive assessment may also be appropriate, and facilitate swifter access to the right support.
Deaf Scotland	Guideline	Rec 1.4	offer contactSCOTLAND/(British Sign Language/BSL) other access service plus telephone & video. Age related dual sensory loss?
Forth Valley Patient Public Partnership	Guideline	Rec 1.5	Follow up could be spelt out but covered to some extent in monitoring
Faculty of Health Sciences, Oxford Brookes University	Guideline	Rec 1.5	This suggests using a screening questionnaire, but 1.5 suggest that a screening questionnaire is not valid. This is contradictory and muddling. It is not useful guidance. It could say "use of a screening questionnaire may help in eliciting other symptoms, but it should not be used as the only criterion for making a diagnosis."
Cardiff and Vale UHB	Guideline	Rec 1.5	Do not rely solely on screening questionnaires .. doesn't seem to fit with line 23. If not, say why not
Asthma UK/British Lung Foundation	Guideline	Rec 1.5	It may be helpful to identify here which methods, beyond screening questionnaires, should be used.
Chartered Society of Physiotherapy	Guideline	Rec 1.5	Will there be a specific recommendation for a screening tool (with provisos) until validated ones are developed?
Royal College of General Practice England,	Guideline	Rec 1.5	The guidance states categorically that no screening questionnaire is validated or recommended for use. This is especially important as the questionnaires linked to the guidance are secondary care focussed rather than primary care focussed. Advocating the use of an unvalidated tool, that you clearly state should not be relied on is very confusing and could be dangerous and using questionnaires and

Stakeholder	Document	Section	Comments
Wales, Scotland and Ireland			tick boxes may alienate patients who at their initial appointment will require empathy and understanding. The Yorkshire screening tool in particular will miss many symptoms commonly reported in PCS. WE request that the use of screening questionnaires that do not have evidence are removed and this section is changed to, “take a full physical and psychological history, exploring every system in the body to ensure all symptoms are identified”.
British Society of Rehabilitation Medicine (BSRM)	Guideline	Rec 1.5	The importance of using experienced clinicians (doctors, nurses, allied health professionals) for virtual consultations should be emphasised. There is potential with this wording that some services may use administration staff or assistant grades.
UEA/Fifth Sense/The Norfolk Smell and Taste Clinic	Guideline	Rec 1.5	Ultimately persistent smell/taste loss need testing to confirm they are so
Public Health Scotland	Guideline	Rec 1.5	Has this been developed yet?
Science for ME	Guideline	Rec 1.5	1.5 Reword to 'Do not rely solely on screening questionnaires when screening people with possible ongoing symptomatic COVID-19; post-covid-19 tissue damage or post-Covid-19 ME/CFS'. This is because Section 1 is concerned with identifying who requires an assessment, and therefore the process is 'screening' rather than 'assessing' which is covered in Section 2. It cannot be known who has ongoing symptomatic COVID-19 or other post-Covid-19 health issues until they are assessed and certainly until they are screened, so all of those conditions are only 'possible' when the screening is being done.
Co Durham CCG	Guideline	Rec 1.5	See comment 1.4. Questionnaires would ease the burden for local health services that are struggling, so more precise advice would be welcome.
Clinical Effectiveness Southwark	Guideline	Rec 1.5	will there be a recommendation about which screening questionnaire to use?

Stakeholder	Document	Section	Comments
British Psychological Society	Guideline	Rec 1.5	The BPS welcomes 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. 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.
Scottish Intercollegiate Guidelines Network (SIGN) Council	Guideline	Rec 1.5	Add to end of recommendation "...as these have not been validated."
Clinical Advisors to the Scottish Government (Clinical Guidance Cell, Professional Advisory Group)	Guideline	Rec 1.5	This is not helpful unless the context of how a screening questionnaire is used and what it is has been defined. See 1.4 above. Completely agree. Needs MDT assessment and a physical examination.
Royal College of Speech and Language Therapists (RCSLT)	Guideline	Rec 1.5	Could you clarify if you are going to recommend a specific screening tool for this population as NHSE has done? We need to avoid local variation in recognising and addressing people’s rehabilitation needs and ensure that these are clearly identified and met. For a consistent approach there should be utilisation of a common robust tool, NICE should recommend more specifically, for example PICUPS Tool (UKROC Rehabilitation Collaborative, King's College London)
Deaf Scotland	Guideline	Rec 1.5	Will questionnaires be available in languages/various communication methods including BSL?
Chronic Long Covid	Guideline	Rec 1.5	be specific about which screening sessions

Stakeholder	Document	Section	Comments
National Institute for Health Research, Centre for Engagement and Dissemination	Guideline	Rec 1.6	Unclear why this is restricted to age group. Varied symptoms are reported by all age groups
Engender	Guideline	Rec 1.6	It is important to demonstrate cognisance of gender discrepancies in clinical diagnosis. A significant body of sex and gender medical research shows that women are more likely to receive psychological diagnosis reporting the same physical symptoms as men, to receive a generalised anxiety or stress diagnosis that follows them from clinician to clinician or to be labeled difficult. Given the degree of unknowns in long-covid - from symptoms to scale - the risk of misdiagnosis is significant, and the guidance should proactively engage with known gendered biases.
Forth Valley Patient Public Partnership	Guideline	Rec 1.6	Point is covered about development during infection
Faculty of Health Sciences, Oxford Brookes University	Guideline	Rec 1.6	This is muddling. 1.4 is suggesting that one should use a screening questionnaire, 1.5 is suggesting that you should not use a screening questionnair, and 1.6 is explaining why you should not use one. Then 1.7 is stating that decisions should be based on screening. Incoherent!
UK Doctors Long COVID Group	Guideline	Rec 1.6	It should also be highlighted that patients from different cultures, in lower socioeconomic groups and minority communities may find it more difficult to access appropriate assessment and management.
Chartered Society of Physiotherapy	Guideline	Rec 1.6	add “or may have had less severe symptoms in the acute phase”.

Stakeholder	Document	Section	Comments
Long Covid Wales	Guideline	Rec 1.6	Presentations not commonly reported occur in all age groups, not only children or the elderly. Therefore, giving such an example may risk discriminatory practices towards those not fitting this description.
Patient-Led Research for COVID-19	Guideline	Rec 1.6	The inclusion of "(for example, children and older people)" could falsely promote the narrative that rare symptoms of Long COVID are only occurring in children and older adults. We recommend removing the content inside the parentheses. If the intent is to alert clinicians to Long COVID occurring in children and older people, then we suggest adding another paragraph and rewording to "Be aware that children and older people are also experiencing Long COVID."
British Geriatric Society	Guideline	Rec 1.6	There is inadequate information in this sentence, please specify what symptoms they may present with or include a link.
The Society and College of Radiographers	Guideline	Rec 1.6	P4 line 2 What are the most commonly reported symptoms?
Long Covid SOS	Guideline	Rec 1.6	We hope that as more evidence emerges there will be documentation provided to further explain what symptoms are more common in children/the elderly?
BAME Health Collaborative (BHC)	Guideline	Rec 1.6	1.6. Be aware that some people (for example, children and older people) may not have the most commonly-reported new or ongoing symptoms after acute COVID-19 – Comment: What are the most commonly reported new/ongoing symptoms? What these atypical symptoms of COVID-19? A link to recommended resources would be very beneficial to the reader.
Co Durham CCG	Guideline	Rec 1.6	See comment 1.4. As we noted in the scoping document the symptoms have significant crossover with other conditions, so more precise advice would be welcome
British Psychological Society	Guideline	Rec 1.6	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.
Clinical Advisors to the Scottish Government (Clinical Guidance Cell,	Guideline	Rec 1.6	It might be helpful to list here what the "commonly reported" symptoms are.

Stakeholder	Document	Section	Comments
Professional Advisory Group)			
Long Covid Support Group	Guideline	Rec 1.6	Remove '(for example, children and older people)'. In a high proportion of cases, symptoms deviate from the four stated on the NHS website.
Forth Valley Patient Public Partnership	Guideline	Rec 1.7	Excellent incorporation of shared discussions with clinicians
Faculty of Health Sciences, Oxford Brookes University	Guideline	Rec 1.7	This whole section between 1.4 and 1.7 is extremely muddled, and a recipe for disaster. There should be a single recommendation which states that "you should elicit the symptoms that a patient has, if you wish aided through using a structured questionnaire to ensure that commonly experienced symptoms are not missed, and that, as a result of the complete assessment, the clinician should use shared decision-making to consider the next step". It needs to be remembered that a syndrome is no more than a collection of symptoms and possible signs which is entirely arbitrary, and that until and unless there is some evidence-based reason for excluding or including particular symptoms the matter should be left open.
Cardiff and Vale UHB	Guideline	Rec 1.7	Line 4 Based on screening, use shared decision making to discuss and agree 4 with the person whether they need to have an assessment in person. The assessment may well be better via a video link or telephone, so all options should be equally considered
Chartered Society of Physiotherapy	Guideline	Rec 1.7	Is this the result of the telephone video assessment? Please clarify the wording. What about access for people who do not have access to telephone / internet and so may have been excluded (see comment for 1.4)
ICUsteps Peer Support Charity	Guideline	Rec 1.7	This suggests that the next stage after the virtual appointment is to have an assessment in person, but some providers may do this 2nd assessment virtually as well?
Royal College of General Practice England, Wales,	Guideline	Rec 1.7	See comments on screening questionnaires.

Stakeholder	Document	Section	Comments
Scotland and Ireland			
British Society of Rehabilitation Medicine (BSRM)	Guideline	Rec 1.7	It needs to be made clear whether remote assessment is the same as screening. Screening must involve the use of an appropriate assessment tool, and NHS England has given 2 examples in their recent guidance.
British Geriatric Society	Guideline	Rec 1.7	In point 1.5 it is advised not to rely on screening, so this seems to be a contradiction of that point. Clinical decision making will take account of many factors to determine whether assessment in person is necessary.
Oxford University Hospitals NHS FT	Guideline	Rec 1.7	not clear what 'screening refers to here
Patient Safety Learning	Guideline	Rec 1.7	Is this screening/video consultation a temporary measure due to COVID-19 restrictions?
Science for ME	Guideline	Rec 1.7	1.7 The current wording with 'shared decision-making' is likely to lead to too much variation in access to care. Give guidance on when a person should be offered an assessment. Wherever ME/CFS is thought possible, an assessment should be offered and encouraged as it may identify treatable differential diagnoses and a diagnosis of ME/CFS can help the person access support.
West Yorkshire and Harrogate Health and Care Partnership	Guideline	Rec 1.7	It would be useful to identify red flags early in the process to reduce the risk of delay before serious underlying causes are identified.
British Psychological Society	Guideline	Rec 1.7	The BPS very much welcomes the emphasis on shared decision making
Scottish Intercollegiate	Guideline	Rec 1.7	It is not appropriate to advise that practice is based on screening when no validated tool exists. Not consistent with the evidence. Remove.

Stakeholder	Document	Section	Comments
Guidelines Network (SIGN) Council			
Chronic Long Covid	Guideline	Rec 1.7	We requested a panel back in June to look at individual (with chronic Post Covid syndrome) instead of separate clinics. Having been in hospital we can tell you it is being seen as separate origins and no collaboration is happening.
Clinical Advisors to the Scottish Government (Clinical Guidance Cell, Professional Advisory Group)	Guideline	Rec 1.7	Need to define what constitutes “screening”. Essential. Realistic Medicine principles.
Long Covid Support Group	Guideline	Rec 1.7	Remove this point, in line with the suggestion to remove the reference to the type of appointment from section 1.4, leaving this to the discretion of the practitioner, taking into account patient preference.
Royal College of Speech and Language Therapists (RCSLT)	Guideline	Rec 1.7	Part of this will require identifying and referring to the most appropriate healthcare professional to assess in depth, i.e a speech and language therapist for dysphonia. Shared decision making for further assessment, needs to include information around whether the patient is already known to services, (for example to a speech and language therapist), as repeat referrals are appearing which is causing confusion in some teams and repeated contacts to the patient which are unnecessary.
National Institute for Health Research, Centre for Engagement and Dissemination	Guideline	Rec 1.8	As commented on the last version, ensure people in residential settings (e.g. prisons, care homes, children's homes, secure hospitals) have access to assessment and ongoing support within the service

Stakeholder	Document	Section	Comments
Engender	Guideline	Rec 1.8	Access to clinical care must bare in mind the need to fit around women's lives including school drop off and precarious work. Women are less likely to have access to private transport which may increase cost in time and resource of attending if clinics are not easily accessible. Women may be required to bring children with them if they have no childcare. Channels for follow up must meet women's needs, ensuring privacy and not rely on women to make last minute appointments or fall down waiting lists.
Forth Valley Patient Public Partnership	Guideline	Rec 1.8	Clearly set out Support for this and for self management given
Faculty of Health Sciences, Oxford Brookes University	Guideline	Rec 1.8	This is badly worded, and it is discriminating against people who do not happen to fall into one of the underserved or vulnerable groups. It should be phrased that this is offered to everyone, with particular care to ensure that it is offered to the vulnerable groups.
NICE GP Reference Panel	Guideline	Rec 1.8	Is it realistic to proactively contact vulnerable people who have self isolated or tested positive? Large numbers vulnerable people in some practices. the question tool proposed will lead to very long consultations and many of the issues wont necessarily be a consequence of COVID. this would be do-able if restricted to people admitted with COVID
Carers Scotland	Guideline	Rec 1.8	When mentioning organisations that work with vulnerable groups, "and their carers" should be added in order to reach carer organisations.
British Society for Rheumatology	Guideline	Rec 1.8	It may be very difficult for GPs to proactively seek out those with a positive test, as positive results are not necessarily reported to GPs. Also, people can have positive tests via many routes and may not seek medical help in the early stages, especially if they have had mild symptoms.
Royal College of Physicians and Surgeons of Glasgow	Guideline	Rec 1.8	Para 1.8. The impact assessment does not include those who are are in prison. It does not recognise the difficulties in following up homeless people. Proactive follow up is important in many groups. Historically primary care has not had the most robust systems of follow up. Any individual highlighted as having COVID symptoms may need to be followed up in a systematic way so that they are not ignored. Their condition may be such that they cannot ask or be in a position to ask for help.
Royal College of General Practice	Guideline	Rec 1.8	Can the committee consider adding why longer consultations are needed. Suggested change to “providing additional support or extra time in consultations add because covid 19 can affect cognition and slow responses to questions”

Stakeholder	Document	Section	Comments
England, Wales, Scotland and Ireland			
British Society of Rehabilitation Medicine (BSRM)	Guideline	Rec 1.8	Please see comments on 1.1
UEA/Fifth Sense/The Norfolk Smell and Taste Clinic	Guideline	Rec 1.8	Advice can be found at www.fifthsense.org.uk for self-management and onward referral to a specialist clinic where needed
Patient-Led Research for COVID-19	Guideline	Rec 1.8	We completely support this paragraph and believe that it is a model of equitable care of Long COVID.
British Geriatric Society	Guideline	Rec 1.8	The bullet points: "Proactively following up..."- this would entail a huge amount of manpower in general practice, particularly in areas where there has been a high prevalence of disease and resources are still stretched. It also depends on how positive results were coded- or not. Early in the pandemic my understanding is that practices were not given positive test results, and they may have been missed on discharge letters (not always put in the summary reasons for admission) so not coded. There is no way to trawl notes for those who self isolated as their contact would generally have been with 111 or online if symptoms were mild to moderate. Patients with atypical symptoms are likely not to have been diagnosed so would not be possible to search for proactively. The people more likely to access GPs with ongoing symptoms may be the more digitally literate who were younger, had typical symptoms and had heard of long covid in the media. If patients are vulnerable, such as those staying at home due to fears of clinical vulnerability, GPs would need to rely on patients being able to have a phone consultation with or without carer present in the case of poor hearing/ cognition. If family members live some distance away and the patient does not want to risk mixing with them/ taxi, or cannot drive, have no access to video consultation or poor hearing/ cognition, shared decision making could be difficult. In

Stakeholder	Document	Section	Comments
			many practices securing a face-to-face assessment involves double triage with another clinician who would need to agree to offering a face to face appointment. In reality, this may be on a different day with a different clinician. The alternative is home visit by a GP, again needing double triage, offered only if there is no other option for addressing the patient's need within the home, such as district nurses or rapid response nurses, both of whom would not be likely to see assessment of possible ongoing covid symptoms as their role. "raising awareness…"- community pharmacists could be another place to focus dissemination of information about ongoing covid symptoms, particularly if they have contact with housebound patients when delivering their medicines.
Patient Safety Learning	Guideline	Rec 1.8	The Guidance notes that 'raising awareness about possible new or ongoing symptoms of COVID 19 – this may include working with local community leaders or organisations, particularly in vulnerable groups'. Is this guidance directed to individual GPs or Clinical Commissioning Groups and other service commissioners (including NHSEI) with the advice of the RCGPs, patient advisers to the Long COVID task group and others? Also, who is included in these 'vulnerable groups?' Is it clinically vulnerable or communities that already face health inequalities or both?
Public Health Scotland	Guideline	Rec 1.8	How would proactive f/u be achieved – most places don't have f/u clinics for those not admitted or formally diagnosed? Appropriate and quality service provision in the way described will take time and resource to set up. There is the potential for inequalities if there is geographical variation in service provision. Are other similar conditions offered the same level of service?
The Society and College of Radiographers	Guideline	Rec 1.8	P4 line 11 How is extra time defined? Can the stakeholders quantify a recommended period of time?
Science for ME	Guideline	Rec 1.8	We support this recommendation.
Co Durham CCG	Guideline	Rec 1.8	See comment 1.4
British Thoracic Society	Guideline	Rec 1.8	The nature of vulnerable groups could be spelt out
Royal College of Nursing	Guideline	Rec 1.8	We are supportive of this recommendation. The workforce needed to deliver this service needs to be considered and funded effectively. General Practices are likely to be heavily involved in screening, triaging and identifying people, as well as being involved in the provision of this service. This will

Stakeholder	Document	Section	Comments
			potentially be a significant burden if workforce expansion is not considered at a time when there are many delays already e.g. undertaking long-term condition annual reviews for people with conditions such as diabetes and asthma etc. Workforce expansion must also include (support workforce) e.g.-Nursing support workers
Department of Health (Northern Ireland)	Guideline	Rec 1.8	There is also concern in respect of para 1.8.which requires that providers support access to assistance and care following acute Covid-19 in underserved groups. Again it is unclear if the intention is that this would involve active case-finding or not. If the former, then there might be an assumption that the first task would fall to primary care. This raises potentially enormous workload issues for GPs – and as case-finding may not be part of their GMS contract some thought would need to be put into how this would be managed in contract terms and funding. In the absence of the expected numbers involved it is very hard to envisage and plan for the right scale of service required. It might be possible to organise a secondary care-led phone review for all hospitalised patients – and if that is what is envisaged then perhaps it would be helpful to state that. Other comments are: underserved or vulnerable groups" this needs explaining more in the body of the doc-re communication needs/cultural/language. P16 in notes gives good examples-language barriers/LD/Mental health or cultural Additional support should have some examples e.g. interpreters/communication accessible.
West Yorkshire and Harrogate Health and Care Partnership	Guideline	Rec 1.8	There needs to be a face to face alternative to telephone/video consultation as the first assessment for people with access barriers e.g. digital exclusion, limited funding for telephone calls. We need to ensure alternatives to written information are available e.g. a video for people with low literacy, and that translated versions are available. Proactive case finding is very important to help reduce health inequalities, and welcome, but also challenging. There are feasibility concerns about proactively following up all people after a positive COVID test to see if they develop long Covid. If this is recommended, there needs to be further information on resourcing, length of follow up. Working with VCSE organisations would be key to proactive case finding. E.g. work with community leaders and groups to identify people in specific communities who have least access to health services. There is reference to community leaders, which is useful – but it would be helpful to broaden this to the VCSE sector to include charities, voluntary groups etc.
British Psychological Society	Guideline	Rec 1.8	The BPS very much welcomes the recommendation to be proactive in reducing inequalities in access to health care and also the inclusion of examples of ways to achieve this

Stakeholder	Document	Section	Comments
Scottish Intercollegiate Guidelines Network (SIGN) Council	Guideline	Rec 1.8	It is not clear that these recommendations or examples, come from evidence. It is also not clear who is to do this and how they would do it. There will be opportunity costs in utilising staff to do this work. They will be unable to do other work in the health service. At a time when many parts of the NHS are trying to catchup with delays that have inevitably resulted from shut down in Covid, there requires to be clear evidence that this is best use of this resource. I have not seen this evidence in the evidence reviews. This should be removed.
Chronic Long Covid	Guideline	Rec 1.8	You need to offer scans and scintigraphy to locate damage X-rays do not show it. Mris and scintigraphy and mri with ecg is needed.
Clinical Advisors to the Scottish Government (Clinical Guidance Cell, Professional Advisory Group)	Guideline	Rec 1.8	Who has responsibility for this role? Yes. Studies seem to suggest that those who benefit most are those with persistent respiratory symptoms although Greehaulgh b does suggest MSK and nutritional support in addition, for those with MSK impact.
Deaf Scotland	Guideline	Rec 1.8	note vulnerability from conditions, protected characteristics and communication/language barriers
Engender	Guideline	Rec 2.1	Joined up approaches to clinical care are to be welcomed, but must include women's health experts, sexual and reproductive care and cardiology with a expertise in sex difference. The known propensity for women to receive a psychological diagnosis which prevents or delays physical diagnosis must be considered when teams involve mental health expertise and especially as symptom knowledge remains incomplete. Emerging data suggests a high sex disparity in outcomes but this is still in progress, however it is important to respond to women's health needs in the guidance as multi-disciplinary teams are developed so as to ensure all patients receive the highest standard of care.
Forth Valley Patient Public Partnership	Guideline	Rec 2.1	Commend use of holistic Person Centred approach
Faculty of Health Sciences,	Guideline	Rec 2.1	This recommendation misses the most important clinical advice of all. This clinical statement will encourage clinicians to lead the consultation by taking a "focused clinical history", which will be interpreted to mean asking about specific expected symptoms and problems. Given that there is no

Stakeholder	Document	Section	Comments
Oxford Brookes University			evidence base on which to determine what symptoms are or are not common and are or are not important, it is much better to open the consultation (as one should always) by asking the patient to report or recount all the problems that they have of any sort, as long as they believe the problem to be related to Covid 19. Only after that has been completed should the clinician start asking any questions. Another problem that has arisen, after reading paragraph 4.1, is that there is no definition as to what constitutes "a holistic assessment", and who should undertake it and how. In general, a holistic assessment requires a multidisciplinary team. About the only alternative is the general practitioner, because the assessment most certainly requires good knowledge of disease and only a doctor will have this. I would anticipate that a holistic assessment, even a brief and abbreviated one, would take upwards of 20 minutes to complete with an additional 10 minutes for documentation and discussion. Any less time would certainly not be holistic.
The ME Association	Guideline	Rec 2.1	2.1 Why is there no mention of possible investigations that could/should be carried out in primary care at this stage? For example - Would spirometry help in the assessment of lung damage that may be present? An ECG may be appropriate if there are cardiac symptoms.
UK Doctors long COVID group	Guideline	Rec 2.1	Why is there a differentiation between psychological symptoms, and psychiatric symptoms? ? As it is clearly stated that this is a holistic guideline, ‘psychological’ would be the appropriate group term to use
British Society for Rheumatology	Guideline	Rec 2.1	Presumably, the intention is this would occur in GP practices, this needs clarity within the recommendation.
Royal College of Physicians and Surgeons of Glasgow	Guideline	Rec 2.1	This guideline appears to imply that the symptoms must be new since the start of the infection. Many post-infectious syndromes including COVID may be heralded an earlier presentation with symptoms related to another condition, or may first present with worsening symptoms for example asthma, stroke, peripheral neuropathy, cognitive impairment. This is mentioned in Page 5, lines 21-23.
Chartered Society of Physiotherapy	Guideline	Rec 2.1	2.1 Suggest this includes the use of validated screening and assessment tools for all symptoms including health related quality of life.
Royal College of General Practice England,	Guideline	Rec 2.1	Can the committee consider adding the ability to work to functional abilities when assessing patients

Managing the long-term effects of COVID-19
Targeted consultation on draft guideline
Comments table
26/11/2020-01/12/2020

Stakeholder	Document	Section	Comments
Wales, Scotland and Ireland			
UEA/Fifth Sense/The Norfolk Smell and Taste Clinic	Guideline	Rec 2.1	consider assessment of chemosensory dysfunction
Oxford University Hospitals NHS FT	Guideline	Rec 2.1	good that 'psychiatric is specified - I did wonder if depression, anxiety (including health anxiety) and panic should be specified?
The Society and College of Radiographers	Guideline	Rec 2.1	P5 line 25 Is there a specific validated screening tool that is recommended or a number of examples?
Science for ME	Guideline	Rec 2.1	2.0 The guideline appears to be covering a. ongoing Covid-19; b. post-Covid-19 tissue damage such as lung damage and strokes; and c. post-Covid-19 ME/CFS. Assessment approaches, choice of the assessor, diagnostic criteria and safety considerations will vary depending on what is suspected. Separate sections for each may be appropriate. 2.1 Replace 'For people with ongoing symptomatic COVID-19 or suspected post- COVID-19 syndrome who have been identified as needing an assessment...' with 'For people with new or ongoing symptoms after acute Covid-19 who have been identified as needing an assessment...' This is because you don't know if someone has ongoing symptomatic Covid-19 until after the assessment, and because post-Covid-19 syndrome is an amalgam of conditions. 2.1 Replace 'For people with ongoing symptomatic COVID-19 or suspected post- COVID-19 syndrome who have been identified as needing an assessment...' with 'For people with new or ongoing symptoms after acute Covid-19 who have been identified as needing an assessment...' This is because you don't know if someone has ongoing symptomatic Covid-19 until after the assessment, and because post-Covid-19 syndrome is an amalgam of conditions.
Long Covid SOS	Guideline	Rec 2.1	Slightly concerned that by including "psychiatric" here it could be interpreted as a solid option for diagnosis given that many with symptoms of Long Covid have been diagnosed with anxiety and only this in the past We'd like to think that that physical symptoms will be investigated for a physical cause

Stakeholder	Document	Section	Comments
			first. We recognise that any of those that are showing psychiatric symptoms will need to be treated for these as well.
National Guideline Centre	Guideline	Rec 2.1	Recommendation 2.1 alerts to red flags which may suggest another serious underlying cause and should be investigated as suggested in section 3. Again this is compatible with the ME/CFS guidance which alerts to the need to exclude reversible conditions and other medical conditions, through a whole person holistic approach underpinned by a careful history-taking and physical examination.
West Yorkshire and Harrogate Health and Care Partnership	Guideline	Rec 2.1	More specific guidance on the investigations a patient should have before they are referred would be useful, including a list of suggested investigations and timing after acute COVID infection. This would provide clarity on what should be completed in primary care before referral to long Covid assessment clinics, and which patients should be referred to this. It would be helpful to recommend specific tools for assessment (e.g. cross reference to tools recommended in other guidelines). This is to ensure validated tools are used and there is some consistency. There could be a cross-reference to long Covid assessment clinic guidance, which has more specifics on how to do assessments. Red flags also need to be mentioned in this section, and ensuring that people have early access to diagnostics to rule out potential other conditions. Waiting for diagnostic tests could slow people’s progress through the pathway and delay access to support.
British Psychological Society	Guideline	Rec 2.1	The BPS warmly welcome 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. We also welcome the recommendation to undertake a broad assessment. It is not, however, entirely clear what the distinction between “Psychological and psychiatric symptoms” is here, we suggest that perhaps “mental health symptoms” might be a simpler description.
Clinical Advisors to the Scottish Government (Clinical Guidance Cell, Professional	Guideline	Rec 2.1	It does not define who should carry out this assessment and in what environment. It does not state on what criteria an assessment is required. Appreciate lived experience may not have found this to be true but “holistic and person-centred approach” should apply to all patient assessments.

Stakeholder	Document	Section	Comments
Advisory Group)			
Long Covid Support Group	Guideline	Rec 2.1	Section 2 should include detail of the types of physical symptoms as otherwise the impression from the guideline is that this is a largely psychosocial condition. Assessment of people with Long Covid should first and foremost identify and address any organ or multisystem dysfunction. While addressing psychological aspects of chronic ill health is important, this should be seen as a part of the recovery process not the first point of contact or assessment. There is no evidence that people with Long Covid have increased rates of pre-existing or concurrent mental ill health compared with the background population. In the event of a secondary mental health problem being identified, the patient’s physical symptoms should not be dismissed or in any way diminished by this diagnosis.
Neurological Alliance	Guideline	Rec 2.1	We welcome the inclusion of a holistic assessment. We would recommend examination include a behavioural assessment also.
NHS England and Improvement	Guideline	Rec 2.1	The first sentence needs clarification. People who have been identified as needing an assessment. An assessment of what?
Forth Valley Patient Public Partnership	Guideline	Rec 2.2	The wide spectrum of the condition and its constituent features suggests co morbidities may well come into play
NICE GP Reference Panel	Guideline	Rec 2.2	Temperature, heart rate & rhythm, BP, respiratory examination, pulse oximetry, functional status, exclude conditions such as PE and mycarditis.
Faculty of Health Sciences, Oxford Brookes University	Guideline	Rec 2.2	What is the clinical history supposed to focus on? Given the likely nature of the syndrome in many people, this focus should include information about previous similar problems after viral infections or other unexpected events such as trauma. As a significant proportion of people with this syndrome will undoubtedly be suffering a functional illness (which accounts for around 25% of all health service consultations), it is important to set this syndrome and illness in the context of the person's lifetime experience of illness.
NICE GP Reference Panel	Guideline	Rec 2.2	This seems to be addressing how COVID is affecting the person. Need a Rec before this one that mirrors 3.3 eg undertake a systematic history and focused examination to identify non-COVID causes for the symptoms and signs.

Stakeholder	Document	Section	Comments
UK Doctors Long COVID Group	Guideline	Rec 2.2	More emphasis/detail on physical symptoms is required otherwise the impression from the guideline is that this is a largely psychosocial condition. We would like to highlight the following: ? Any rates quoted of psychiatric disorder related to COVID need to take account of the fact that those with pre-existing mental health disorders have a significantly higher risk for COVID?19 infection (a 1·65 times excess) and also present a worse outcome with higher rates of hospitalisation and death (https://doi.org/10.1002/wps.20806). ? Increased rates of psychiatric disorder occur following COVID infection for all patients, in the period between 14 and 90 days after COVID-19 diagnosis, 5·8% of COVID-19 survivors had their first recorded diagnosis of psychiatric illness (F20–F48), compared with 2·5–3·4% of patients in comparison cohorts. Rates were greater for anxiety disorders, insomnia and dementia. Is this related to doctors interacting with these patients more and so making the diagnosis. ? Previous pandemics have shown increase rates of anxiety, depression and PTSD in the whole population, not just those who become unwell. ? In any chronic illness there are increased rates of mental health problems of 37%, this is a consequence of the illness not a cause of it (https://bmcpublichealth.biomedcentral.com/articles/10.1186/s12889-019-6623-6). ? Evidence to date suggests that in long COVID only 20-25% have psychological disorder, which includes insomnia, which would not traditionally be considered a psychiatric disorder by psychiatrists. ? Therefore services for patients with long COVID should not be fronted with IAPT staff or a predominance of mental health staff. o Bearing in mind this is a multisystem disorder a thorough specific system enquiry of physical symptoms should be asked and any warning symptoms flagged for thorough investigation ? The current statement is lacking in granularity and underplays the physical component of the illness. ? It should be emphasised that a positive PCR test is not necessarily required for a clinical diagnosis to be made. ? The conditions associated with COVID should be outlined and it made clear that these are not confined to patients who suffered serious acute illness, and that they may appear at any time during the course of the illness including after 12 weeks. Specifically this list should include: peri- and myocarditis, arrhythmias, autonomic disorders including PoTS, increased risk of VTE, microvascular angina, new onset diabetes, new onset of allergies and angioedema, MCAS, asthma, arthritis, persistent pyrexia, neuropathies and myelopathies, thyroiditis, persistent gastrointestinal disturbance and weight loss
Chartered Society of Physiotherapy	Guideline	Rec 2.2	2.2 Should we add investigating precipitating factors to the assessment, and whether these are linked to changes in symptoms? Also add another bullet point “Impact on existing comorbidities”.

Stakeholder	Document	Section	Comments
Royal College of General Practice England, Wales, Scotland and Ireland	Guideline	Rec 2.2	Can the committee consider adding the criteria for diagnosis here? No test or antibody is required. Clinical diagnosis is enough?
Long Covid Wales	Guideline	Rec 2.2	This section has a concerning focus on mental health and underemphasises that this is a physical illness. Not disregarding the fact that severe and chronic illness are risk factors for mental health conditions, however there is currently no evidence that people with Long COVID have an increased incidence of new mental health issues compared to the general population. Secondly, such mental health issues would be a consequence of the illness rather than a symptom of the illness itself. A small subcategory of patients have presented with neuropsychiatric symptoms directly linked to the infection, such as hallucinations, which should be given appropriate focus (please see https://academic.oup.com/brain/article/143/10/3104/5868408) . However, a much stronger focus needs to be had on making an initial assessment of the physical aspects of the illness as this is the main presentation. We also wish to comment that a large proportion of the anxiety expressed in those with Long COVID is directly associated with having experienced dismissal by medical personnel, despite presenting clear acute medical signs and symptoms, as well as gaslighting of the Long COVID illness and its associated complex multi-system presentation. Our hopes are that a national guideline accurately depicting the illness will aid in reducing any such stressful stigma and mistreatment. Furthermore, this section must cover conditions associated with COVID-19 and Long COVID and highlight that they may appear at any time during the course of the illness. This includes, but is not limited to, myopericarditis, microvascular angina, arrhythmias, thromboembolic disease including PE and cerebral venous thrombosis, MCAS, POTS, dysautonomia not including POTS, Guillain-Barré syndrome, encephalitis, ADEM, prolonged pyrexia, new onset diabetes, new onset allergies, arthritis, neuropathies and myelopathies. The clinical history must include a detailed systems enquiry, with any red flags managed with appropriate urgency. Lastly, regarding line 24 - this needs to make reference to the fact that a diagnosis of COVID-19 can equally be made either by laboratory confirmation or on clinical grounds. Positive PCR or antibody tests are not a prerequisite for a diagnosis.
British Society of	Guideline	Rec 2.2	This focussed clinical history must include past & present medical & mental health conditions, which could be either adversely impacted by COVID -19 or may make that individual more vulnerable to the

Stakeholder	Document	Section	Comments
Rehabilitation Medicine (BSRM)			consequences. Patients with pre-existing neurological disorders associated with fatigue eg: Multiple Sclerosis, Acquired Brain Injury, may experience even greater fatigue. Where patients have pre-existing physical impairments, deconditioning will have a greater impact on function. Those with pre-existing mental health disorders may be at greater risk of self harm or misuse of alcohol/drugs Some people experience “functional” disorders where no medical causation has been identified; there is a risk that any post-COVID symptoms could be misinterpreted & so they could be denied access to post COVID services
UEA/Fifth Sense/The Norfolk Smell and Taste Clinic	Guideline	Rec 2.2	questions about anosmia, hyposmia, parosmia, phantosmia, hypogeusia, dysgeusia, ageusia
British Geriatric Society	Guideline	Rec 2.2	Again, the difficulty lies in identifying older patients who may have had atypical symptoms and no diagnosis made at the time, as well as the variability in an individual's ability to remember time scales if they have been in lockdown for many months or have cognitive impairment.
Oxford University Hospitals NHSFT	Guideline	Rec 2.2	need to consider past medical history - premorbid health and functioning is a predictor of response to a variety of insults.
British Psychological Society	Guideline	Rec 2.2	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 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. 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. In-hospital experiences, particularly delirium but also hypoxia and encephalitis, are also significant risk factors for persistent difficulties
Royal College of Paediatrics	Guideline	Rec 2.2	There should be a specific question about the symptoms of Paediatric Multisystem Inflammatory syndrome (PMIS) – many children had presumed asymptomatic initial infection with late syndrome of

Stakeholder	Document	Section	Comments
and Child Health			Kawasaki/Toxic shock/Sepsis symptoms. Reference: Radia et al Paediatr Respir Rev 2020 Aug 11;S1526-0542(20)30117-2.
Clinical Advisors to the Scottish Government (Clinical Guidance Cell, Professional Advisory Group)	Guideline	Rec 2.2	Given the role and efficacy of antibody tests, should we be looking to test for Covid antibodies as a means to diagnose this condition? Requires a person-centered non algorithmic approach given the breadth of symptoms potentially presented.
Engender	Guideline	Rec 2.3	Gender differences must be considered, including women's greater provision of care, childcare and household work, greater likelihood of becoming a lone parents, slightly higher risk of poverty, exposure to men's violence and domestic abuse, reliance on social security, greater chance of precarious or part time or precarious work, likelihood of working in sectors most effected by public health measures, greater reliance of public transport, higher proportion of persons with co-morbidities - all of which and more are likely to play a part in women's access to treatment and recuperation. Evidence from BHF showed that women had poorer outcomes when returning home from hospitalisation for cardiac issues because their lives were incompatible with recovery programmes. Gender sensitive care plans are a critical element of positive health outcomes for women.
Royal College of Occupational Therapists	Guideline	Rec 2.3	RCOT fully supports this important focus upon the person’s ability to participate in their daily occupations.
Forth Valley Patient Public Partnership	Guideline	Rec 2.3	Essential in a holistic assessment
Faculty of Health Sciences, Oxford	Guideline	Rec 2.3	This is a strange recommendation. When you say discuss, do you mean ask about? I do not think that this has been written by a clinician. How can a clinician discuss how a person's life and activities have been affected? Up to this point you have not even suggested that question should be asked about these areas, making it impossible to discuss something that one does not know about.

Stakeholder	Document	Section	Comments
Brookes University			
The Poverty Alliance	Guideline	Rec 2.3	For households in precarious or low paid employment, it may also be beneficial to understand the attitudes of their employers to the pandemic and how they have supported staff . In addition it is helpful to understand any wider income pressures faced by the patient as a result of their condition.
Asthma UK/British Lung Foundation	Guideline	Rec 2.3	We would add the person's ability to carry out caring responsibilities as a specific point to consider.
Chartered Society of Physiotherapy	Guideline	Rec 2.3	2.3: Add “and how these impact upon their symptoms”
Long Covid Wales	Guideline	Rec 2.3	Persons used to regular exercise, naturally, will be upset by the fatigue due to Long COVID, but those with an active intellect may equally be distressed by the brain fog.
UEA/Fifth Sense/The Norfolk Smell and Taste Clinic	Guideline	Rec 2.3	Weight loss and weight gain can manifest from chemosensory dysfunction
British Geriatric Society	Guideline	Rec 2.3	In the absence of typical initial symptoms, older patients may put changes in mobility and independence down to deconditioning during lockdown, with social isolation reducing their social network and potentially increasing cognitive impairment.
Science for ME	Guideline	Rec 2.3	There's an implicit assumption that the symptoms the person is presenting with are related to Covid-19. That could lead to differential diagnoses not being considered. Also, the current focus of 2.3 is on the acute illness rather than the subsequent symptoms which are being assessed. Instead use 'Discuss how the person's life and activities have been affected by the symptoms following acute COVID-19'.
Chest Heart & Stroke Scotland	Guideline	Rec 2.3	At present there is a gap in terms of the impact that COVID-19 can have on relationships e.g. partners, children, wider family and friends. The guidance states 'Discuss how the person’s life and activities have been affected by COVID-19, for example their work or education, mobility and independence' can 'relationships be added?

Stakeholder	Document	Section	Comments
West Yorkshire and Harrogate Health and Care Partnership	Guideline	Rec 2.3	It is very helpful that consideration of people's lives and activities is included so clearly. This needs to include social roles e.g. caring responsibilities. It would also be useful to risk assess support that people have at home, e.g. do they have a carer, what additional support is required for them/their carer?
British Psychological Society	Guideline	Rec 2.3	We warmly welcomes the focus on disruption to activities and social role in addition to assessment of specific physical symptoms. 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 viral illness (Moss-Morris et al 2011, Hulme et al 2017). It is therefore critical that clinicians enquire not only about overall disruption, but also specific pattern of activity. 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 et al 2017) and has been identified as being a significant predictor of persistent difficulties following a viral infection. We therefore strongly recommend that a recommendation to assessment sleep pattern and quality is included. 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. Refs: 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? Psychological medicine, 41, 1099–1107 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, Journal of Psychosomatic Research, 99,120-129 Pedersen. M et al (2017) Sleep–wake rhythm disturbances and perceived sleep in chronic fatigue syndrome. Journal of Sleep Research, 26, 595-601
Scottish Intercollegiate Guidelines Network (SIGN) Council	Guideline	Rec 2.3	Sections 2.3-2.5 are simply about good clinical practice. They should be considerably shortened to encourage holistic empathic care. None of this is specific to COVID-19 and will lose readers.
Clinical Advisors to	Guideline	Rec 2.3	Essential

Stakeholder	Document	Section	Comments
the Scottish Government (Clinical Guidance Cell, Professional Advisory Group)			
National Voices	Guideline	Rec 2.3	We strongly support the integration of physical and mental health approaches proposed in this guideline. It is encouraging to see that empathy, listening, surfacing feelings of worry and distress, and also the needs of family members or carers all get mentioned. This strikes us as progressive, and much needed across all long term conditions care, but sadly far too often absent from mainstream approaches.
Forth Valley Patient Public Partnership	Guideline	Rec 2.4	Again dialogue between patients and clinicians an essential feature of this guideline
Faculty of Health Sciences, Oxford Brookes University	Guideline	Rec 2.4	Another badly worded recommendation. It would be better phrased, "enquire not only about their experience of symptoms, but also about any secondary feelings of worry or distress that they experience and also what their concerns are about these particular symptoms?"
The Poverty Alliance	Guideline	Rec 2.4	Enquire if the patient is facing any additional costs as a result of their symptoms for example childcare due to fatigue , higher fuel costs as a result of longer periods at home.
UEA/Fifth Sense/The Norfolk Smell and Taste Clinic	Guideline	Rec 2.4	impact on work/other activities
Patient Safety Learning	Guideline	Rec 2.4	This should be expanded to include how this will inform advice on return to work/education, access to support, financial support (fit notes, benefits assessment etc) or where this advice/support is available. We believe this should also consider making reasonable adjustments such as extended appointment

Managing the long-term effects of COVID-19

Targeted consultation on draft guideline

Comments table

26/11/2020-01/12/2020

Stakeholder	Document	Section	Comments
			times for patients, particularly those who are experiencing cognitive symptoms. Or allowing them to bring a companion to face-to-face appointments, where they may not otherwise be allowed due to current infection control measures.
Science for ME	Guideline	Rec 2.4	2.4. We support this paragraph; acknowledgement of a person's experience is important.
The Richmond Group of Charities	Guideline	Rec 2.4	The guidance should also reference loneliness in addition to the separate but often related issue of social isolation.
British Thoracic Society	Guideline	Rec 2.4	This should generally stick to confirmed cases (Antigen or Antibody). Otherwise there is potential for confusion.
Chest Heart & Stroke Scotland	Guideline	Rec 2.4	The examples provided are example 'activities of daily living, feelings of social isolation, work and education, and wellbeing'. Can the potential impact on relationship be acknowledged here to ensure this is given consideration?
British Psychological Society	Guideline	Rec 2.4	We warmly welcome the recommendation to develop an individualized understanding of the impact of COVID-19 and to normalize the experience of distress. The recommendation is phrased as discussing the persons "experience" of their symptoms; this is extremely important; however it is also important to understand their beliefs about their symptoms. There is considerable evidence to show the link between illness beliefs and recovery after viral infection (see Hulme et al 2017 for systematic review) 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) 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, Journal of Psychosomatic Research, 99,120-129.
Clinical Advisors to the Scottish Government (Clinical Guidance Cell, Professional	Guideline	Rec 2.4	Empathy should apply with any patient assessment. It might be helpful in the preamble to describe the lived experience to highlight the concerns of this patient population rather than make occasional platitudes to the patients through the document. To me this is patronising to the healthcare professional as well as the patient. This section should be a statement of fact "Record the impact on their activities of daily living…" "Do a mental health examination" There are tools to assess mental health which have not been suggested where as other tools have been, equally without and evidence base. Should this be suggested? Essential to measure impact on patient.

Stakeholder	Document	Section	Comments
Advisory Group)			
Engender	Guideline	Rec 2.5	There is a delicate balance here where women have a carer, especially a family member to ensure that patient-led care is delivered (see Engender, 2019, Our Bodies Our Rights.) There is also a need to ensure family carers, likely to be women, have necessary support and information to enable them to care and minimise effects on the own wellbeing.
Forth Valley Patient Public Partnership	Guideline	Rec 2.5	Recognition of the role of family and carers in outcome is commended
Faculty of Health Sciences, Oxford Brookes University	Guideline	Rec 2.5	A poorly constructed recommendation which is difficult to understand even at the second or third reading. Are you suggesting that if a person needs support with communication, then the clinician should talk to family members? Or are you suggesting that, in every case, the clinician should talk to family members? It needs to be written much more clearly.
Carers Scotland	Guideline	Rec 2.5	There is a need for the guideline to specifically discuss where a person lacks capacity and where family/carers should be involved in discussions. We would suggest that an additional recommendation is added to the outline of gathering the best information to inform diagnosis and treatment. We would suggest that it is good practice to seek to talk to carers to gather information, particularly where they have been providing care prior to the person having COVID.
Chartered Society of Physiotherapy	Guideline	Rec 2.5	2.5: Broaden this point. ‘Provide opportunities for people to bring a family member / carer / support worker etc to attend appointments to help support communication, memory, cognition, fatigue and shortness of breath (as needed).
Science for ME	Guideline	Rec 2.5	2.5 We support this paragraph; if the person wishes, it can be very helpful for family or carers to speak for them.
British Psychological Society	Guideline	Rec 2.5	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. 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. Family members and

Stakeholder	Document	Section	Comments
			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.
MSD Ltd	Guideline	Rec 2.5	MSD suggests that the decision-making process for face-to-face consultations should aim to facilitate presence of a trusted relative/friend/carer with the person if feasible. Consider that this could be a key aspect in helping person to feel adequately supported through management of ongoing symptomatic COVID-19 or post-COVID-19 syndrome.
Clinical Advisors to the Scottish Government (Clinical Guidance Cell, Professional Advisory Group)	Guideline	Rec 2.5	Not clear what this means and who should do this? Reasonable to get third party view. Common useful practice in usual clinical assessment with patient's consent.
Royal College of Speech and Language Therapists (RCSLT)	Guideline	Rec 2.5	Please build in communication support mechanisms, such as support from a speech and language therapist for people who have communication challenges. This will be essential to ensure that people understand discussions and can contribute fully to decisions.
Deaf Scotland	Guideline	Rec 2.5	what if carer/other needs communication/language support?
Engender	Guideline	Rec 2.6	As previously noted, the incomplete picture of clinical symptoms heightens a real risk that women will receive poorer quality care. Sex and gender differences in symptom reporting and evaluation must be monitored and not allowed to influence care quality.
Patient Forth Valley Patient Public Partnership	Guideline	Rec 2.6	Spelling out of what these may be to raise awareness of those involved in their care formal and informal as well as those attempting self management themselves
Faculty of Health	Guideline	Rec 2.6	Be aware is not a recommendation

Stakeholder	Document	Section	Comments
Sciences, Oxford Brookes University			
The ME Association	Guideline	Rec 2.6	Why is there no list of symptoms that are commonly being reported? Possibly in two lists - one covering symptoms that are common to any PVFS and those that may represent end organ damage from COVID... Symptoms consistent with a PVFS: Debilitating fatigue which is often activity/exercse induced Cognitive dysfunction Dysautonomia - Orthostatic intolerance, PoTS and postural hypotension Headaches Myalgia Unrefreshing sleep Problems with thermoregulation/temperature control Post exertional malaise/symptom exacerbation Symptoms that are consistent with possible end organ damage from COVID 19 Shortness of breath Chest pains Arrhythmias and palpitations Abdominal pain and diarrhoea Loss of taste and smell Fevers
Long Covid Wales	Guideline	Rec 2.6	With reference to the examples of conditions associated with Long COVID (see comments to section 2.2), signs and symptoms associated with Long COVID can be insidious in onset and fluctuating in nature, so asking explicitly is beneficial.
British Geriatric Society	Guideline	Rec 2.6	Please could the "wide-ranging and fluctuating symptoms" be spelt out in this section, as there is an assumption that clinicians reading the guidelines will know these already, but they may be looking up the guidelines for advice about what to look for.
Science for ME	Guideline	Rec 2.6	2.6 Given the wide range of possible post-Covid-19 conditions, from stroke to ME/CFS, the scope of this paragraph is too broad to be useful.
British Psychological Society	Guideline	Rec 2.6	We agreed this is important, 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.
Chronic Long Covid	Guideline	Rec 2.6	you could include our catalogue I sent NICE the 182 effects for referencing which is an open living document
Long Covid Support Group	Guideline	Rec 2.6	Positioning this point in this section implies that wide-ranging and fluctuating symptoms do not occur during the acute phase, which does not reflect the experience of people living with Long Covid. Also, there is a distinction to be made between fluctuating symptoms and those that relapse and remit (i.e. symptoms go away before returning).

Stakeholder	Document	Section	Comments
Royal College of Speech and Language Therapists (RCSLT)	Guideline	Rec 2.6	'Be aware that people can have wide-ranging and fluctuating symptoms after COVID-19, which can change in nature over time…' please add: and may change in priority to the person.
Forth Valley Patient Public Partnership	Guideline	Rec 2.7	Effects of dealing with comorbidities spelt out as above
Faculty of Health Sciences, Oxford Brookes University	Guideline	Rec 2.7	Be aware is not a recommendation
Patient Advisory Group to the CFS/ME Research Collaborative (CMRC)	Guideline	Rec 2.7	This concept is usually termed 'post-exertional malaise', rather than 'post-exercise malaise'; the distinction means that a worsening of symptoms may be expected after any exertion, not simply 'exercise'. Post-exertional malaise is considered by leading ME/CFS researchers and clinicians to be a hallmark symptom of the illness. Patients with this symptom who meet the diagnostic criteria for ME/CFS, and who do not have any additional symptoms that are not characteristic of ME/CFS, should surely be considered for an ME/CFS diagnosis.
Chartered Society of Physiotherapy	Guideline	Rec 2.7	2.7 line 17 should read post-exertional malaise not 'post-exercise malaise'
UEA/Fifth Sense/The Norfolk Smell and Taste Clinic	Guideline	Rec 2.7	may not offer chemosensory symptoms first

Stakeholder	Document	Section	Comments
Patient-Led Research for COVID-19	Guideline	Rec 2.7	The research that this paragraph pulls from does not reflect the Long COVID experience. There are several issues with the ZOE app and the COVID Symptom Study. Primarily, they counted users who discontinued using the app as “recovered”, even when they had multiple symptoms at their last entry, which dramatically undercounts the prevalence of Long COVID (the COVID Symptom Study’s app prevalence estimates are a magnitude lower than other prevalence estimates, including https://www.medrxiv.org/content/10.1101/2020.09.01.20184937v1 and https://www.medrxiv.org/content/10.1101/2020.10.07.20208702v1.full.pdf). Secondarily, they did not ask about common cognitive and neurological symptoms that are prevalent in Long COVID, which leaves any analysis based on their symptoms to be lacking. In fact, there is evidence that non-hospitalized patients may be more likely to have neurological symptoms and have symptoms for a longer duration (https://onlinelibrary.wiley.com/doi/full/10.1002/mco2.13). There is too little known about what symptoms are more indicative of the development of Long COVID. Patient-Led Research is conducting analysis on this question currently and will update NICE/SIGN/RCGP with our findings. Until then, we suggest the removal of this paragraph and the consideration of removing this study from the list of approved evidence.
British Geriatric Society	Guideline	Rec 2.7	This is very useful information and could do with being more obvious, in bullet points, earlier in the document so it is spotted sooner for busy clinicians scanning through the information during consultations.
Action for M.E.	Guideline	Rec 2.7	This recommendation should state the likelihood of the person going on to develop M.E./CFS. Draft guideline in development GID-NG10091 states that M.E./CFS should be suspected if a person has had symptoms for 6 weeks in adults. These symptoms can include the post-exertional malaise, fatigue and shortness of breath mentioned under 2.7. Denying people a diagnosis of M.E./CFS can lead to harmful methods of rehabilitation or management which go against best evidence. Studies have shown that M.E./CFS is associated with pandemic influenza infection https://pubmed.ncbi.nlm.nih.gov/26475444/
Patient Safety Learning	Guideline	Rec 2.7	We would suggest including the basis of these risk factors.
Science for ME	Guideline	Rec 2.7	2.7 Given 'post-covid-19 syndrome' appears to be an amalgam of ME/CFS and/or various types of tissue damage caused by Covid-19, there seems little value in suggesting clusters of symptoms to predict it. This is especially so given that paragraph 2.8 says that the clinician should not rely solely on clusters of symptoms to predict who will get 'post-Covid-19 syndrome'. 2.7 'post-exercise malaise' is mentioned. It is not clear if this is referring to the cardinal symptom of ME/CFS, 'post-exertional

Stakeholder	Document	Section	Comments
			malaise'. Our understanding is that post-exertional malaise (PEM) is occurring in people with 'Long Covid'. PEM can occur after any physical activity, not just exercise, and also after cognitive effort. 'Post-exertional malaise' should be used in this guideline.
ME Action UK	Guideline	Rec 2.7	Reference is made to “post-exercise malaise” - we are confused as to where this term has come from, as this symptom is normally named post-exertional malaise (PEM). The draft ME/CFS guideline from NICE suggests renaming this to post-exertional symptom exacerbation (PESE). Most experts and all recent diagnostic criteria consider PEM/PESE a hallmark of ME/CFS. Where this symptom is present the person should be assessed for ME/CFS, and the draft ME/CFS guideline advice on energy management and physical activity, including the explicit recommendation against graded exercise therapy, should take precedence, due to the significant evidence of harm identified by NICE. Evidence also suggests that rest in the early stages of ME/CFS may lead to the best chances of recovery (Vink, 2019 https://www.mdpi.com/2075-4418/9/4/124), yet this guideline doesn’t once mention the potential need for rest. Evidence is yet to be presented that people experiencing post-exertional symptom exacerbation after COVID-19 do not meet the criteria for ME/CFS. Seeing as ME/CFS is commonly triggered by viruses, it is likely that a sizable proportion have COVID-19-triggered ME. After the previous outbreak of SARS in Hong Kong, 27% were left with ME/CFS (Lam et al, 2009). We propose changing this sentence to “Be aware that people who have multiple symptoms in the first week of illness, older people, and people with persistent shortness of breath, fatigue, post-exertional symptom exacerbation (PESE) or palpitations at 4 to 6 weeks may be more likely to develop long term symptoms or other viral triggered conditions.” This recognises both that we don’t know what long COVID is, and that these symptoms could in some cases be explained by other diagnoses.
National Guideline Centre	Guideline	Rec 2.7	Recommendation 2.7 alert to the possibility of post-COVID-19 syndrome but does not provide any distinguishing features from ME/CFS. We note that in the ME/CFS guidance post exercise malaise is referred to as post-exertional symptom exacerbation.
Co Durham CCG	Guideline	Rec 2.7	More specific advice about the likely length of various symptoms would help primary care decision-making i.e what can we regard as within 'normal limits'
British Psychological Society	Guideline	Rec 2.7	Agree
Clinical Advisors to	Guideline	Rec 2.7	Should we not be comparing this to a return to baseline or near baseline here? Reasonable but makes diagnosis potentially challenging.

Stakeholder	Document	Section	Comments
the Scottish Government (Clinical Guidance Cell, Professional Advisory Group)			
Long Covid Support Group	Guideline	Rec 2.7	Remove this paragraph since not enough is known. These assertions (which we believe are based on the views of the KCL/ZOE Covid Symptom Study app) do not ring true to people in our Long Covid Support Group, and risk prejudicing the assessment and treatment of people who do not fall into these categories. As acknowledged in the Rationales section (page 17 lines 22-24), ‘There were too many uncertainties in the evidence to provide definitive risk factors for developing post-Covid-19 syndrome and the panel did not want professionals to rely heavily on these’. The ZOE/KCL app findings are unreliable for the following reasons: 1. Long Covid appears to have been defined by the investigators without patient involvement, therefore, it is not underpinned by physical reality as experienced by people with Long Covid. For example, the investigators define Long Covid as having five symptoms or more; for those with the condition it is the effect (rather than the number) of symptoms that is relevant. 2. People are deemed to have recovered if they have reported 5 days or more with no symptoms. This disregards the relapsing-remitting nature of Long Covid, one of the main defining features as experienced by patients, and points to flawed methodology. Recovery must be defined by people with Long Covid, it is meaningless for investigators to decide what recovery looks like. 3. Bias in sampling. Many people with Long Covid stopped reporting in the ZOE app because it was not user friendly. Because of the extremely limited list of symptoms, there was a burden on users to, daily, list all of their other symptoms in free text. 4. What the ZOE/KCL app has, in fact, discovered is that middle aged white women are the demographic most likely to persevere in reporting in the app. The ZOE/KCL app was designed to be a sentinel for infectious outbreaks, which it does well. They extended the scope into Long Covid without amending the study design in order to achieve that new aim. It is a poor tool to investigate Long Covid and it is unfortunate that it has had so much influence.
Engender	Guideline	Rec 2.8	This should not interfere with the need to establish trends among particular groups.
Forth Valley Patient Public Partnership	Guideline	Rec 2.8	More detail could be provided

Stakeholder	Document	Section	Comments
Faculty of Health Sciences, Oxford Brookes University	Guideline	Rec 2.8	This recommendation seems out of place. This is a guideline about the management of the syndrome, which has arbitrarily and inadvisedly been set at starting at 12 weeks. If you are going to add statements concerning prediction at an earlier stage, then it needs to be made clear that this guideline relates to management from the outset. However, if this is a guideline for people established as having the syndrome which is defined (inadvisedly) as starting at 12 weeks, then 2.8 does not make sense. Or, perhaps, what you really mean is that a diagnosis should not be made, or negated, by considering what symptoms had been present at earlier stages. The point of this statement needs to be considered.
UEA/Fifth Sense/The Norfolk Smell and Taste Clinic	Guideline	Rec 2.8	Smell loss most predictive for Covid 19
British Geriatric Society	Guideline	Rec 2.8	It is not clear what is being referred to with the phrase “certain clusters of symptoms”; more clarity would be welcome, which clusters of symptoms are being referred to?
Patient Safety Learning	Guideline	Rec 2.8	What other factors should be considered? It would be beneficial to include examples.
British Society for Immunology	Guideline	Rec 2.8	It should also be noted that many clinicians still assume that the risk for long COVID must be greater in those who were hospitalised with severe COVID, yet there appears little correlation with the severity of the acute event.
National Guideline Centre	Guideline	Rec 2.8	The warning in recommendation 2.8 to not rely on a cluster of symptoms is appropriate.
British Psychological Society	Guideline	Rec 2.8	Agree
Long Covid Support Group	Guideline	Rec 2.8	Points 2.8 and 2.9 are confusing because the language shifts between ‘Post-Covid-19 syndrome’ and ‘long term effects of Covid-19’ – what is the distinction that the points are trying to make?

Stakeholder	Document	Section	Comments
NHS England and Improvement	Guideline	Rec 2.8	This statement need clarification. What else should/could be relied upon alongside symptom clusters to predict who is likely to develop post-COVID-19 syndrome?
Forth Valley Patient Public Partnership	Guideline	Rec 2.9	Gradual decline considered and highly relevant
Lifestyle, Exercise and Nutrition Improvement (LENI) Research Group	Guideline	Rec 2.9	The potential of psychological effects of COVID-19 should also be acknowledged for younger people as well.
Faculty of Health Sciences, Oxford Brookes University	Guideline	Rec 2.9	While this is not an unreasonable statement, it needs to be balanced by the reverse, namely that a decline in elderly person may be due to many other courses other than Covid 19, and this is probably more likely. The problem that needs to be avoided is the attribution of everything to a previous infection with Covid 19 when other more common and treatable conditions are in fact the cause.
British Geriatric Society	Guideline	Rec 2.9	The long-term effects referred to here could be attributed to those caused by lockdown per se, or the expected trajectory of decline in frailty, so older people and their carers/ family (and GP) may assume lockdown, or hospital admission, rather than atypical covid, caused these symptoms, especially in the absence of a positive swab, which would mean they are less likely to come forward for assessment.
Science for ME	Guideline	Rec 2.9	2.9 It is not clear what the 'long-term effects of Covid-19' means. Clearly is the person had a stroke during a covid-19 infection, the long term effects could well be different to if the person suffered lung damage. The paragraph is too broad to be useful.
British Thoracic Society	Guideline	Rec 2.9	We note that there is some evidence that an increased frequency of falls is seen in elderly people with or after COVID

Stakeholder	Document	Section	Comments
British Psychological Society	Guideline	Rec 2.9	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.
Clinical Advisors to the Scottish Government (Clinical Guidance Cell, Professional Advisory Group)	Guideline	Rec 2.9	Not sure how this helps? They would still need assessed for common causes of decline.
Long Covid Support Group	Guideline	Rec 2.9	Points 2.8 and 2.9 are confusing because the language shifts between 'Post-Covid-19 syndrome' and 'long term effects of Covid-19' – what is the distinction that the points are trying to make?
Royal College of Speech and Language Therapists (RCSLT)	Guideline	Rec 2.9	Loss of interest in eating and drinking indicates a role for dietitians and speech and language therapists to support safe eating and drinking, especially critical after acute admission where nutrition is negatively impacted upon. This workforce should be highlighted in the Guideline. We suggest that you consider referencing the following data: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7683822/ High numbers of patients who were intubated and tracheostomised, and so are also likely to experience the impact of insult to the upper airway and require support to manage resulting dysphonia and dysphagia. Please see the following evidence https://bjanaesthesia.org/article/S0007-0912(20)30678-4/fulltext Loss of eating and drinking can also mask an underlying swallowing problem which may or may not be related to long-covid. Referral to speech and language therapists is key to understanding the underlying cause and preventing health deterioration through malnutrition and chest infections.
Forth Valley Patient Public Partnership	Guideline	Rec 2.10	Dealt with in 3.2 in more detail
Lifestyle, Exercise and Nutrition Improvement	Guideline	Rec 2.10	Please recommend appropriate, validated screening tools. As COVID-19 specific ones do not currently exist, it would be appropriate to recommend pre-existing (or adapted from pre-existing) ones related to COVID-19 symptoms.

Stakeholder	Document	Section	Comments
(LENI) Research Group			
Faculty of Health Sciences, Oxford Brookes University	Guideline	Rec 2.10	But there are no screening tools that are useful for cognitive symptoms in terms of making a diagnosis of those symptoms. You should make yourself aware of this important publication. https://doi.org/10.1093/brain/awaa224
UK Doctors Long COVID Group	Guideline	Rec 2.10	Cognitive symptoms ? What is the validated screening tool that will be used and will it be sensitive enough to pick up more subtle symptoms? ? Is it possible to use the Great British IQ test online tool? This is more thorough than the current GP screening tools for cognitive assessment although it doesn't cover executive functioning
Chartered Society of Physiotherapy	Guideline	Rec 2.10	2.10: What happens if someone has a score indicative of needing onward referral from cognitive screen?
Royal College of General Practice England, Wales, Scotland and Ireland	Guideline	Rec 2.10	Can the committee provide guidance on which cognitive assessment tool is appropriate. This is likely to be different depending on whether this is an older person with pre-existing mild cognitive impairment and a decline in memory, or a child presenting with new onset neuropsychiatric symptoms or a previously well adult reporting 'brain fog' symptoms.
Long Covid Wales	Guideline	Rec 2.10	We would point out that word-finding difficulties seems to be a commonly reported symptom in Long COVID. Some of us who have taken part in Clinical Linguistics research have found it hugely reassuring that our being lost for words is not a symptom of early dementia, because we have not lost words from memory, but instead we are suffering from "specific lexical retrieval difficulty".
British Society of Rehabilitation	Guideline	Rec 2.10	There is a range of cognitive assessment tools, but there will be none specific to this situation. One of the roles of the post-COVID MDT (which should include psychologists/neuropsychologists, occupational therapists, Rehabilitation Medicine & Mental Health) would be to specify for individuals which is the most appropriate cognitive assessment tool. Experience in acquired brain injury is that it is

Stakeholder	Document	Section	Comments
Medicine (BSRM)			often family members who recognise changes in cognition & behaviours rather than the patient. It is therefore essential that the views of family members are sought as they may pick up more subtle changes.
British Geriatric Society	Guideline	Rec 2.10	Please specify an example of a validated screening tool. Would 6CIT be one such tool, and would delirium be a potential cause of cognitive decline post covid infection, given that delirium can last for months, in which case which tool would be recommended?
Patient Safety Learning	Guideline	Rec 2.10	What are the validated screening tools? Where can these be accessed?
Science for ME	Guideline	Rec 2.10	2.10 Cognitive symptoms experienced by people with other post-infectious syndromes are often not picked up by standard cognitive tests because the problems typically fluctuate and are related to sustained exertion. Patient reports suggest that the same applies to post-Covid-19 ME/CFS.
UK Faculty of Public Health	Guideline	Rec 2.10	page 5 line 24 we wondered if there were well validated tools for this specific assessment that might be referenced
West Yorkshire and Harrogate Health and Care Partnership	Guideline	Rec 2.10	It would be helpful to recommend specific tools for assessment that are validated (e.g. cross reference to tools recommended in other guidelines)
British Psychological Society	Guideline	Rec 2.10	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. 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 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. Ref: British Psychological Society (2020) Meeting the psychological needs of people recovering from severe coronavirus (Covid-19)

Stakeholder	Document	Section	Comments
			https://www.bps.org.uk/coronavirus-resources/professional/psychological-needs-recovering-severe-coronavirus
Scottish Intercollegiate Guidelines Network (SIGN) Council	Guideline	Rec 2.10	Please give an example
Clinical Advisors to the Scottish Government (Clinical Guidance Cell, Professional Advisory Group)	Guideline	Rec 2.10	Should give examples/reference.
NHS England and Improvement	Guideline	Rec 2.10	How would you know what the person's scores were prior to the new cognitive symptoms? Would this not be a baseline measurement from which future scores could be compared to assess improvement or worsening?
Association of British Neurologists	Guideline	Rec 2.10	… and specifically asking what the evidence for performing and using a cognitive test in patients selected purely on the basis of "new cognitive symptoms" as a screen, and instead suggesting taking a full history including from an informant first. And, not assuming that anyone with cognitive symptoms has COVID related organic brain disorder, recognising that some of "brain fog" that is reported is likely to be occurring as part of a functional cognitive disorder which may require specific interventions and further research.
Engender	Guideline	Rec 3.1	This must include links with contraception, sexual health, fertility, maternity, endocrinology, cardiology and women's health experts.
Cardiff and Vale UHB	Guideline	Rec 3.1	urgently to the relevant acute services if they have 4 symptoms that could be an acute or life-threatening complication, for example hypoxaemia or oxygen desaturation on exercise, signs of severe

Stakeholder	Document	Section	Comments
			lung disease. cardiac chest pain or multisystem inflammatory syndrome (in children). This is likely a similar list that we identified may be helpful in p 2 line 24 red flags.
UK Doctors Long COVID Group	Guideline	Rec 3.1	Needs more red flag conditions included – ie. neurological emergencies, acute thyroid problems, acute pancreatitis, thromboembolic complications, anaphylaxis. ? It is important to note that atypical chest pain is common in women with significant underlying cardiac pathology and should not be dismissed as it does not fit the 'typical cardiac' chest pain familiar to doctors, the data for which was based on a predominantly male participant cohort.
British Society for Rheumatology	Guideline	Rec 3.1	This section requires further clarification. It is unclear who patients will be referred to, where services will sit, and which specialty(ies) will be driving the care and management of this group of patients. There is also little detail about what to do if there are problems, such as fibrotic lung disease, or chronic fatigue. Chilblains, inflammatory arthritis, and vasculitis are not even mentioned, although all have been described as sequelae (so by definition are long COVID). Furthermore, the investigation section provides little steer as to what tests need doing in what patients. We are concerned by the lack of specifics as to when investigations are needed and who will arrange these investigations. Is this expected of primary care or will this be co-ordinated by a specialist service? We suggest adding 'Only' at the beginning (or before the 'if') to ensure that acute services are not overwhelmed by referrals for everyone with post-COVID shortness of breath on exertion.
Chartered Society of Physiotherapy	Guideline	Rec 3.1	3.1: This is a general comment for Section 3: Does this section need general recommendations for undertaking and interpreting findings and onward referral pathways. For example, in 3.4: What is the purpose of the exercise tolerance test? If completed what will they do with the findings? Will it be repeated? When and by whom?
Royal College of General Practice England, Wales, Scotland and Ireland	Guideline	Rec 3.1	Can the committee change "symptoms in line 5 to "signs". The guidance currently states that patients should be referred on the basis of acute symptoms yet then uses examples which are all signs. There is a full stop between lung disease and chest pain. Suspect it should be a comma.
Long Covid Wales	Guideline	Rec 3.1	The list of examples for conditions requiring urgent referral is quite restrictive. Other relevant examples would be neurological emergencies, thromboembolism including PE and cerebral vein thrombosis, acute pancreatitis, acute thyroid issues, or anaphylaxis.

Stakeholder	Document	Section	Comments
British Geriatric Society	Guideline	Rec 3.1	Please specify levels of "hypoxaemia or oxygen desaturation on exercise" with an example of which exercise challenge is appropriate, for example, is this referring to walking 40 steps, to help guide remote clinical decision making. Given the prothrombotic nature of covid, should acute pleuritic chest pain be mentioned in addition to cardiac?
Science for ME	Guideline	Rec 3.1	Change - use the wording from the Section 2 heading 'Refer people with ongoing or new symptoms following acute Covid-19', as it doesn't pre-suppose a diagnosis in a section talking about further investigations.
British Thoracic Society	Guideline	Rec 3.1	We suggest specifying 'severe hypoxaemia', since mild hypoxaemia is common in people with resolving lung injury who have been hospitalised for acute COVID and does not in itself necessitate re-referral to acute services.
West Yorkshire and Harrogate Health and Care Partnership	Guideline	Rec 3.1	Rehabilitation referral is important and should be mentioned at the start of this section. It is a bit unclear what role long Covid assessment clinics play in the further investigations referral. Guidance on when patients should be referred from primary care would be helpful.
Public Health England	Guideline	Rec 3.1	Line 7, P6 – Should be a ‘,’ not a ‘.’ between ‘disease’ and ‘cardiac’
British Psychological Society	Guideline	Rec 3.1	Agree
Royal College of Paediatrics and Child Health	Guideline	Rec 3.1	It was suggested that details or references should be included where the reader can access details on multisystem inflammatory syndrome in children.
Mast Cell Action	Guideline	Rec 3.1	Include anaphylaxis , particularly in children with Multi system imfalmmatory syndrome. Consider a diagnosis of Mast Cell Activation Syndrome, NHS tests are available for mast cell mediators, histamine , prostaglandin and tryptase.
Clinical Advisors to the Scottish	Guideline	Rec 3.1	For relevant symptoms that are identifiable objectively e.g. have persistent or new symptoms. Greehaulgh A cites BTS guidance on those who have significant respiratory illness requiring a chest x ray after 12 weeks. Spruit guidance paper recommends assessment by an MDT, again that pulmonary

Stakeholder	Document	Section	Comments
Government (Clinical Guidance Cell, Professional Advisory Group)			and respiratory rehab are 'better than none'.Greehaulg hB cites a tiered approach. This may provide a useful framework for clinicians and patients to work together.
Long Covid Support Group	Guideline	Rec 3.1	What about urgent problems arising from viral infection, but not emergency symptoms? A significant proportion of Long Covid patients have evidence of organ pathology and impairment. This is increasingly evident in the literature that is being published. Among the members of our Long Covid Support Group the following conditions are represented, among others: a. Myocarditis/pericarditis b. Microvascular angina c. Cardiac arrhythmias including atrial flutter and atrial fibrillation d. Dysautonomia including postural orthostatic tachycardia syndrome (PoTS) e. Mast cell activation syndrome (MCAS) f. Interstitial lung disease g. Thromboembolic disease (pulmonary emboli/cerebral venous thrombosis) h. Myelopathy and neuropathy i. Renal impairment j. New onset diabetes k. New onset allergies and anaphylaxis Line 8: Remove '(in children)'. A multisystem inflammatory syndrome is believed to exist also in adults.
NHS England and Improvement	Guideline	Rec 3.1	Typo - erroneous full stop between disease and cardiac. Should be a comma. Refer for any signs of severe lung disease or could some more helpful description be added as to which kind of severe lung disease?
National Voices	Guideline	Rec 3.1	It might be useful to flag the availability of social prescribing and other services that can support people with their emotional and practical needs in this part of the guideline. Many people will need help with benefits or other financial matters, some might need to talk to social services for the first time. It can be extremely helpful to be able to support people with the ongoing, holistic relationship a link worker can establish. https://www.nationalvoices.org.uk/our-work/SocialPrescribing
Engender	Guideline	Rec 3.2	There is a need for particular care and monitoring to prevent women being dismissed or barriers to quality care.
NICE GP Reference Panel	Guideline	Rec 3.2	Have or will NHSE / commissioners made arrangements with local CMHTs for this proposal?

Stakeholder	Document	Section	Comments
Forth Valley Patient Public Partnership	Guideline	Rec 3.2	Severe is outlined Pressures on services a factor but less severe i.e .mild to moderate could be dealt with by GPs
Polymyalgia Rheumatica and Giant Cell Arteritis Scotland (PMR-GCA Scotland)	Guideline	Rec 3.2	Will this be available, given that psychiatric services are presently struggling to see even those with acute symptoms? Will more resources, both financial and staffing, be provided? referral in itself should not be seen as fulfilling a requirement; only when help is actually being provided do people benefit.
UK Doctors Long COVID Group	Guideline	Rec 3.2	Please include a statement that these patients should also be managed appropriately for the physical aspect of their ongoing COVID-19 symptoms as well as their psychiatric condition.
Long Covid Wales	Guideline	Rec 3.2	Psychiatric symptoms related to COVID-19 have been found to be of organic nature; it is vital this is not disregarded if a referral to psychiatry is considered. Please see https://academic.oup.com/brain/article/143/10/3104/5868408
British Society of Rehabilitation Medicine (BSRM)	Guideline	Rec 3.2	This list should include other concerning symptoms/red flags. Some will have cardiac involvement, so may experience palpitations or tachycardia, with cardiac decompensation. Stridor should be included, & can occur just on exertion, & needs urgent ENT evaluation. Necrotising pancreatitis is a recognised consequence, & can occur severl weeks after acute infection, so acute abdominal pain should trigger urgent referral. Any new neurological symptoms
Oxford University Hospitals NHSFT	Guideline	Rec 3.2	good so see this - can we specify what 'severe psychiatric symptoms ' means a little more?
Science for ME	Guideline	Rec 3.2	Change - use the wording from the Section 2 heading 'Refer people with ongoing or new symptoms following acute Covid-19', as it doesn't pre-suppose a diagnosis in a section talking about further investigations.
ME Action UK	Guideline	Rec 3.2	It would seem more logical to list the tests for physical abnormalities - 3.3 to 3.6 - before recommendation 3.2 on referral to a psychiatrist. If people with severe physical symptoms can be relieved by appropriate symptomatic treatment, that may well contribute to substantial improvement in

Stakeholder	Document	Section	Comments
			any mental health issues. Throughout the document, there is an emphasis on mental health issues despite nearly all the evidence on symptoms referenced demonstrating that fatigue is more common than anxiety.
National Guideline Centre	Guideline	Rec 3.2	This applies to anyone and not just people with ongoing symptomatic COVID-19 or suspected post-COVID-19 syndrome. Does this recommendation suggest the risk is higher in this population?
British Psychological Society	Guideline	Rec 3.2	Agree
Clinical Advisors to the Scottish Government (Clinical Guidance Cell, Professional Advisory Group)	Guideline	Rec 3.2	If required
Deaf Scotland	Guideline	Rec 3.2	people affected by deafness have higher than average risks of mental ill health, compounded by COVID mitigation. Are there specific risks/mitigation for this group/others with communication barriers also at high risk?
Forth Valley Patient Public Partnership	Guideline	Rec 3.3	Spells out bloods and lung function Again reference to primary care services could be expanded
NICE GP Reference Panel	Guideline	Rec 3.3	Clinical testing to exclude conditions as appropriate, such as PE, myocarditis, LVF, secondary bacterial infection : FBC CRP U&Es LFTS D-Dimer BNP, CXR, ECG, D-dimer, troponin, creatine kinase,
Lifestyle, Exercise and Nutrition Improvement	Guideline	Rec 3.3	The possibility of including vascular function-specific tests should also be noted, as now it is believed that COVID-19 has a serious cardiovascular effect as well.

Stakeholder	Document	Section	Comments
(LENI) Research Group			
Faculty of Health Sciences, Oxford Brookes University	Guideline	Rec 3.3	A remarkably unhelpful recommendation. I think what you mean is that the clinician should, as is entirely normal, consider a differential diagnosis and then undertake appropriate investigations to distinguish between the alternative diagnoses. This recommendation is either stating the obvious on the assumption that someone has made an alternative diagnosis, or is forgetting to remind the person that they should consider alternative diagnoses. The whole guideline is written from the perspective that everything is attributable to Covid 19, rather than placing it in a real clinical context where alternative diagnoses always have to be considered.
Cardiff and Vale UHB	Guideline	Rec 3.3	3.3 We think you should state the referral criteria from PC to Secondary Care more clearly – so for example should have some/at least one of: hypoxia at rest/exercise, Physical exam shows signs of significant lung/heart disease, abnormal ECG/CXR or simple lung function test, failed low complexity exercise test (walk test is fine), abnormal POTS test to qualify for referral to resp or cardiology. Line 17 Lung function tests. This needs further consideration on what the guidance recommends, as though we agree this is a very necessary test, currently this is seen as aerosol generating, and primary care are largely not undertaking these, so guidance is needed as to what can be done, where and by whom. There is likely a need for a primary care based respiratory physiologist led service but not necessarily in every GP practice.
The ME Association	Guideline	Rec 3.3	Section 3: Why is there no mention of the new network of Post/Long COVID clinics and how contact details and protocols can be accessed 3.3 Post viral syndromes can precipitate other medical conditions that have remained silent up until now. So clinical judgement needs to be used to assess whether persisting symptoms are simply linked to COVID. For example: Could persisting abdominal pain and diarrhoea be due to an inflammatory bowel disease being precipitated? I have been dealing with such as case.... Could muscle pain be due to a polymyalgia rheumatica being precipitated - as has been reported? Could muscle weakness be due to myasthenia gravis? - as reported in the Annals of Internal Medicine. Consider including a Composite Autonomic Function Scale to assess symptoms relating to dysautonomia 3.3 refer to other inflammatory markers in people with persisting bowel symptoms following COVID - ie calprotectin

Stakeholder	Document	Section	Comments
UK Doctors Long COVID Group	Guideline	Rec 3.3	The list of initial investigations should also include ECG, and blood tests to be done should be stated not suggested, they should include ferritin, ESR, LDH, CK, D-dimer, Trop, BNP on top of the investigations already mentioned ? Please include a note that many initial investigations may be normal, but that does not exclude the existence of significant pathology.
British Society for Rheumatology	Guideline	Rec 3.3	Lung function testing is not generally available in primary care, and secondary care lung function testing is currently severely compromised because of COVID. We suggest advising oxygen saturation on air with onward referral to respiratory medicine for those with significant desaturation.
Royal College of Physicians and Surgeons of Glasgow	Guideline	Rec 3.3	Mandal et al suggest D-dimers also may be used to investigate ongoing symptoms and signs. Thrombo embolic disease is common in COVID Thorax. 2020 Nov 10;thoraxjnl-2020-215818. doi: 10.1136/thoraxjnl-2020-215818
Asthma UK/British Lung Foundation	Guideline	Rec 3.3	It should be flagged that lung function testing is difficult to carry out currently as it is deemed aerosol creating, and there is likely to be a significant backlog as large numbers of people with suspected lung conditions have not been able to access diagnostic tests during the pandemic. Because of this, the person could still be waiting for a lung function test 12 weeks or more beyond their infection. This shouldn't prevent full consideration of the possibility of a long-covid diagnosis. It may be helpful to refer to the British Thoracic Society guidance on resumption of lung function testing https://www.brit-thoracic.org.uk/covid-19/covid-19-resumption-and-continuation-of-respiratory-services/
Royal College of General Practice England, Wales, Scotland and Ireland	Guideline	Rec 3.3	The investigation section is not clear on time lines. When should these tests be completed? It would be useful if a visual aid were developed to indicate whether investigations are all performed at the point of initial contact, or if some are in the 4-12 week stager an others 12 weeks or more.
Long Covid Wales	Guideline	Rec 3.3	The list of investigations also needs to mention B12, Vitamin D, ESR, D-dimer, BNP, clotting, CK and LDH, as well as ECG and CXR. There should be a low threshold for non-invasive cardiac investigations such as Holter monitoring and echo. There is a disproportionate focus on possible lung pathology and its investigations. Please see examples of conditions associated with COVID-19 mentioned above (2.2) and the COVERSCAN study and adopt a more balanced approach to review all systems https://www.medrxiv.org/content/10.1101/2020.10.14.20212555v1.full.pdf.

Stakeholder	Document	Section	Comments
British Society of Rehabilitation Medicine (BSRM)	Guideline	Rec 3.3	In addition pituitary function screening be included for those with persistent fatigue - 9am cortisol, TFTs & IGF1 are the commonly used pituitary function screening tests. Screening for previously undiagnosed diabetes Given cardiac involvement is possible – ECG, echocardiography.
The Royal College of Obstetricians & Gynaecologists	Guideline	Rec 3.3	Lines 12-17. Suggest include a pregnancy test for women of childbearing age.
UEA/Fifth Sense/The Norfolk Smell and Taste Clinic	Guideline	Rec 3.3	see above comments about self-testing Ultimately, psychophysical testing is needed to confirm dysfunction
Patient-Led Research for COVID-19	Guideline	Rec 3.3	We recommend adding the following to the examples of blood tests: EBV and CMV titers and an APS panel [Anticardiolipin IgG, IgM and IgA; anti-?2 glycoprotein I IgG, IgM, and IgA; and anti-phosphatidylserine/ prothrombin (aPS/PT) IgG and IgM, Lupus Anticoagulant (see https://stm.sciencemag.org/content/12/570/eabd3876)]. We also recommend screening for serologic tryptase as well as 24-hour urine tests for n-methyl histamine, prostaglandin-D2, or its metabolite, 11?-prostaglandin-F2? (https://tmsforacure.org/tests/) for indications of Mast Cell Activation Syndrome (https://pubmed.ncbi.nlm.nih.gov/32920235/). We recommend adding imaging as a bullet point (for example, cardiac MRI and imaging to assess for thrombosis and stroke) as patients are being diagnosed with myocarditis (https://pubmed.ncbi.nlm.nih.gov/32747875/) as well as thrombosis (https://pubmed.ncbi.nlm.nih.gov/33149655/).
British Geriatric Society	Guideline	Rec 3.3	Regarding blood testing in the community, it would be useful to know what would be expected in the results of these blood tests in ongoing covid or would they be normal? Having guidance may reduce unnecessary risk each time a blood test is taken in the surgery or in the home. Along similar lines, is there any evidence about whether GPs should consider stopping any specific medications in older

Stakeholder	Document	Section	Comments
			patients at higher risk of long covid? Lung function tests are usually requested by respiratory physicians rather than GPs.
The Royal College of Pathologists	Guideline	Rec 3.3	B/ Section 3.3: This is not an exhaustive list. E.g. Troponin, Vitamin D and ECG and should be included.
On behalf of Public Health Scotland	Guideline	Rec 3.3	Will a standard screening blood panel be established, or left up to local units to create their own?
Science for ME	Guideline	Rec 3.3	Add: For people with post-exertional malaise or significant fatigue, carry out an assessment for ME/CFS. (NICE guideline on ME/CFS - https://www.nice.org.uk/guidance/gid-ng10091/documents/draft-guideline)
ME Action UK	Guideline	Rec 3.3	This section must include a recommendation to assess for ME/CFS. Other symptoms are mentioned with recommendations for investigations to assess them. People with long term symptoms post-COVID-19 should be asked if they are experiencing significant fatigue and/or post-exertional malaise/post-exertional symptom exacerbation (PEM/PESE), and those who are must be assessed for ME/CFS. The guidance on management of fatigue and other symptoms in ME/CFS is very different from fatigue in other illnesses, with a strong focus on energy management and staying within the person’s energy envelope. Relying on generalised fatigue management here is likely to harm this population. The care of people newly diagnosed with ME/CFS should follow the new ME/CFS guideline from NICE which is currently in draft form after a significant update. Nearly 80% of people with ME/CFS report an infectious onset to their symptoms, and evidence from previous epidemics demonstrates a significant minority will go on to develop ME/CFS. Furthermore, the evidence this committee has considered demonstrates that fatigue is the most common symptom for those with long COVID. It is of utmost importance that this guideline recognises that ME/CFS can be triggered by COVID-19, and we are surprised to see this omission. If you take just one thing from our submission, we strongly urge you to add a bullet point that says: “For people with post-exertional symptom exacerbation or significant fatigue, carry out assessment for ME/CFS.”
National Guideline Centre	Guideline	Rec 3.3	Recommendation 3.3 is non-specific about which tests should be undertaken and when. It also does not give any information on how to rule out diagnoses for which there is not a diagnostic test, such as ME/CFS. This should be considered, especially as the exercise tolerance test recommended in recommendation 3.4 may make people with ME/CFS worse.

Managing the long-term effects of COVID-19
Targeted consultation on draft guideline
Comments table
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Stakeholder	Document	Section	Comments
Co Durham CCG	Guideline	Rec 3.3	3.3. As we noted in the scoping comments, it would be helpful to add a comment about the use of antibody tests
Clinical Effectiveness Southwark	Guideline	Rec 3.3	It seems strange to suggest blood tests without any guidance. Should all patients be getting these? Are these the only test we should offer? What about BNP? What about other investigations such as sputum culture or ECG? Also lung function testing is not available at the moment due to Covid infection concerns- is there something else NICE would suggest in its stead at present such as serial peak flows? I think it would better to say 'investigate as appropriate', or give specific guidance on what investigations for what symptoms.
British Thoracic Society	Guideline	Rec 3.3	The recommendation for lung functions tests needs to be explained. What tests? How to do them in current climate? Some reference to where this will be undertaken should be included ? We suggest that consideration could be given to PEF monitoring which is especially useful before full lung function services become widely accessible again.
West Yorkshire and Harrogate Health and Care Partnership	Guideline	Rec 3.3	This recommendation needs more specific information on tests/assessments that are recommended. This is important to ensure that appropriate, validated tests are used. Cross references to other NICE guidelines or the long Covid assessment clinics guidance could be included. It could be clearer that this is guidance for further assessments for the cohort of patients requiring more specialist support.
Sheffield ME and Fibromyalgia Group	Guideline	Rec 3.3	Add to this section 'People with post-exertional symptom exacerbation should be assessed against the diagnostic criteria for ME/CFS as per the new draft NICE ME/CFS guideline'.
British Psychological Society	Guideline	Rec 3.3	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.
Royal College of Paediatrics and Child Health	Guideline	Rec 3.3	It was suggested that also checking Vitamin D levels in the blood tests may be helpful. Although the reviewer recognised that there is no evidence to support this yet. Consider including asking about changes in hearing and/or balance in the clinical history taken in either primary or secondary care assessments and make appropriate referral for assessment. The Munro paper on hearing/tinnitus in adult patients is in the included references/evidence. There is no robust evidence to cite yet for changes to hearing and/or balance post Covid in children, however virus induced hearing loss is well

Stakeholder	Document	Section	Comments
			known in children. As information is still emerging it would be prudent to consider asking about changes in hearing and balance in children post Covid.
Clinical Advisors to the Scottish Government (Clinical Guidance Cell, Professional Advisory Group)	Guideline	Rec 3.3	I am against giving examples here. This should be tailored to the individual and decided on after the consultation. The risk of putting in examples is that every patient expects any or all of these test to be done. The ability to get PFTs done is limited so I would not have this even mentioned as there is no evidence base and this should be targeted to those with certain symptoms. A detailed recommendation on which patients PFTs may useful in might be better. And symptoms presented.
Long Covid Support Group	Guideline	Rec 3.3	This is a very short list of tests. Why these tests? There is a need for assessment of several different body systems, including a check for diabetes such as HBA1C, since Covid can cause new diabetes, which, if missed, can worsen prognosis. 1. Rubino, F. et al. New-Onset Diabetes in Covid-19. N. Engl. J. Med. 383, 789–790 (2020). 2. Reddy, P. K., Kuchay, M. S., Mehta, Y. & Mishra, S. K. Diabetic ketoacidosis precipitated by COVID-19: A report of two cases and review of literature. Diabetes Metab. Syndr. Clin. Res. Rev. 14, 1459–1462 (2020). 3. Naguib, M. N., Raymond, J. K. & Vidmar, A. P. New onset diabetes with diabetic ketoacidosis in a child with multisystem inflammatory syndrome due to COVID-19. J. Pediatr. Endocrinol. Metab. (2020) doi:10.1515/jpem-2020-0426. 4. Coate, K. C. et al. SARS-CoV-2 Cell Entry Factors ACE2 and TMPRSS2 Are Expressed in the Microvasculature and Ducts of Human Pancreas but Are Not Enriched in ? Cells. Cell Metab. (2020) doi:10.1016/j.cmet.2020.11.006.
Neurological Alliance	Guideline	Rec 3.3	There remains the possibility that neurological sequelae may occur, and this should be monitored. We would therefore suggest that neurological investigations, including neurophysiology and neuroimaging, be recommended here in order to exclude other diagnoses.
Forth Valley Patient Public Partnership	Guideline	Rec 3.4	Useful inclusion Again where to be conducted
Lifestyle, Exercise and Nutrition	Guideline	Rec 3.4	To receive a complete picture, we would recommend other elements of the Senior Fitness test or the 2- or 6-minute walking test, as this is considered to be a reliable functional fitness fitness and tolerability test, which is safe and requires minimal experience and training by the assessor.

Stakeholder	Document	Section	Comments
Improvement (LENI) Research Group			
Faculty of Health Sciences, Oxford Brookes University	Guideline	Rec 3.4	Is there any evidence that doing a formal test is necessarily any better than asking someone what their tolerance is in terms of time that they can walk, or whether or not they can manage to go up and down stairs? As few people will know what protocol is appropriate "to carry out the test safely", and as this is not defined, most wise people will not follow this recommendation. It is also unlikely to be helpful, and spending time asking someone to what extent their ability to undertake activities that require physical exercise is restricted would be much more useful as it would give insight into their practical problems.
Patient Advisory Group to the CFS/ME Research Collaborative (CMRC)	Guideline	Rec 3.4	Be aware that for patients who meet the criteria for an ME/CFS diagnosis exercise beyond their ‘energy envelope’ is contra-indicated (see draft ME/CFS guidelines) and can cause long term harm. Mechanisms must be put in place for patients to report deterioration in health following exercise testing. ME/CFS patients had no mechanism to have their reports of the harms of exercise recognised for many years, to the detriment of many.
The ME Association	Guideline	Rec 3.4	3.4 The use of exercise testing requires further clarification. Exercise testing does not form part of the clinical assessment of people who have a PVFS or ME/CFS. It may have some value in assessing cardiorespiratory function where this has been affected by the acute infection.. However, is there any evidence to indicate that this is a safe procedure to carry out in people with Long COVID who are experiencing post exertional symptom exacerbation.? Research evidence indicates that a two day cardiopulmonary exercise test can be helpful in the clinical assessment, diagnosis and monitoring of people with PVFS and ME/CFS. However it can also cause an exacerbation of symptoms. Exercise testing in people with Long COVID needs to carry some sort of health warning
UK Doctors Long COVID Group	Guideline	Rec 3.4	This should include saturations during exercise. The sit-stand test is crude and does not identify subtle issues adequately, a 6 minute walk test or stair test should be included, ideally the latter as it more clearly demonstrates breathlessness and falls in oxygen saturation. ? Due to frequent reports of sleep disturbance and oxygen saturations falling at night, sleep studies should be considered at secondary care level.

Stakeholder	Document	Section	Comments
British Society for Rheumatology	Guideline	Rec 3.4	Given the challenges of many primary care appointments being remote, it doesn't seem feasible that these assessments (ie 1-min sit-to-stand test & 3-mins active stand test or 10-min if suspect postural tachycarida syndrome) be undertaken in a primary care setting and the rather exhaustive list of investigations being suggested is a concern. GPs (or others) should not be asked to carry out these specific tests, as they are time consuming, and do not appear to have a clear evidence base at present. Obviously, it would be ideal as part of a research project. Presumably, it is aiming to identify those who have lost exercise tolerance, but too vague at present. There are no specific details on how these assessments would then alter the further management of patients. It is likely that staff will need training in how to undertake these assessments and the guideline doesn't provide specifics as to how these then alter management.
Royal College of General Practice England, Wales, Scotland and Ireland	Guideline	Rec 3.4	The sit to stand test is a new test for primary care and will need explicit instruction on how to do this if it is to be included. Currently, there does not appear to be any validation of the test or recommended protocol to use. If this is left to the individual to learn and perform themselves it could be dangerous • Measuring pulse oximetry is essential and has been missed off the list of observations and is essential. Levels of desaturation that requires referral needs to be clarified • The rationale for measuring blood pressure is not clear and may not be possible DURING the test. Des the committee mean before and after the test • Under the "rationale for suggested protocols" it states that no protocol could be recommended as their effectiveness had not been reviewed, if we do not know their effectiveness then why are they being recommended? • Should this only be performed in secondary care? If so this needs to be made clear in the guidance.
Long Covid Wales	Guideline	Rec 3.4	Any exercise test needs to record saturations, as desaturations with movement are commonly seen. Furthermore, for such tests to be conducted safely the person performing the test must have a thorough understanding of post-exertional malaise (see comments to sections 5.1, 5.6, and Key recommendations for research 17-18).
British Society of Rehabilitation Medicine (BSRM)	Guideline	Rec 3.4	We are unsure why this specific test has been selected. Is this to be carried out during a face to face assessment with appropriate monitoring & support should a patient become physiologically compromised, or is there a suggestion is could be carried out via remote assessment (potentially dangerous). It should be made explicit that if this test is carried out, it is appropriately supported & with patient selection. Patients with physical impairments (leg pain, leg weakness) will not be able to carry out this test

Stakeholder	Document	Section	Comments
Patient-Led Research for COVID-19	Guideline	Rec 3.4	We are concerned about the suggestion of exercise tests without specific instructions for the type of test. If this is to evaluate potential dysautonomia, we recommend the 10-minute NASA lean test. However, by recommending exercises tests without the specific guidance to test for dysautonomia, physicians may perform tests that result in harm to the patient. In Patient-Led Research for COVID-19's research, we found that 89% of respondents experienced worsening or relapses of symptoms after physical or mental exertion. We do not have evidence to support that this worsening of symptoms is guaranteed to improve. Therefore, an exercise test could have a detrimental effect on patients. Further, a biomarker that can be used to assist with the diagnosis of ME/CFS is not detectable until the second day of consecutive-day cardiopulmonary exercise tests (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6417168/). Until we have evidence of a meaningful exercise test for Long COVID patients, it is dangerous to recommend them.
British Geriatric Society	Guideline	Rec 3.4	Are GPs expected to conduct exercise tolerance tests or is this specifically for those trained to do it in secondary care? If GPs will be expected to do these tests, "to carry out the test safely", a link to the protocol would be important and there would need to be clear guidance on what the risks are, what constitutes a positive test, and what difference this makes to further management for the patient, as well as how specific this test is for ongoing covid.
Action for M.E.	Guideline	Rec 3.4	For those with post-exertional malaise an exercise intolerance test can worsen symptoms, sometimes for a considerable period of time. If there are different sub-groups of people with long-Covid, as referenced in the guideline, then extra care needs to be given to ensure that any such examination is not harmful.
Science for ME	Guideline	Rec 3.4	Add 'As a subset of people with post-COVID-19 symptoms are likely to have ME/CFS, caution should be taken on any exercise tests. People should not be pushed to the limit of their exertion as the harmful consequences may not be immediately apparent.'
UK Faculty of Public Health	Guideline	Rec 3.4	Page 6 line 18 and page 7 line 3) We wondered if the physiological tests referred to here needed more explanation for the normal GP who may not be familiar with them
ME Action UK	Guideline	Rec 3.4	"Offer an exercise tolerance test suited to the person's ability -..." It is good that these tests are considered - so long as they are undertaken sensitively with regard to those seriously ill, and take into account that in the case of post-exertional malaise, negative side effects may not appear until 24-72 hours later.

Stakeholder	Document	Section	Comments
National Guideline Centre	Guideline	Rec 3.4	Recommendation 3.4 causes concern because some people with ME/CFS report a severe worsening of symptoms after attempting a bout of increased exercise; it is not yet known whether post COVID-19 patients will similarly experience devastating fatigue after exercise. Therefore, it will be important to monitor not only the physiological response during the test but the post-exercise symptoms for up to 3 days after testing. Also, as cardiac arrhythmias have been described in COVID-19 it would be important to monitor ECG recording during this test.
Clinical Effectiveness Southwark	Guideline	Rec 3.4	exercise tolerance test is mainly about oxygen desaturation but this only mentions heart rate and blood pressure. Blood pressure is not normally measured in the exercise test. Is this a mistake?
Clinical Advisors to the Scottish Government (Clinical Guidance Cell, Professional Advisory Group)	Guideline	Rec 3.4	No evidence base for this in COVID as such although I acknowledge it may be useful. In the test it does not refer to post COVID respiratory symptoms. It would not be relevant e.g. in some one without exertional dyspnoea. I would not suggest this without an evidence base.
Long Covid Support Group	Guideline	Rec 3.4	Remove reference to exercise tests, as these can trigger worsening of symptoms.
Royal College of Speech and Language Therapists (RCSLT)	Guideline	Rec 3.4	There should be a mention of assessment and consideration of dysfunctional breathing
Deaf Scotland	Guideline	Rec 3.4	what prep for skills/assessment? Inclusive communication, pre-prepared film, symbols etc clarity of purpose/expectation
Forth Valley Patient Public Partnership	Guideline	Rec 3.5	As in 3.4

Stakeholder	Document	Section	Comments
Faculty of Health Sciences, Oxford Brookes University	Guideline	Rec 3.5	None
NICE GP Reference Panel	Guideline	Rec 3.5	Postural symptoms/giddiness may follow weight loss during the acute illness which reduces the requirement for BP medication. It would be good to have a rec that reflects this e.g. consider whether the symptoms could be related to a changing need for medication following COVID acute illness
Patient Advisory Group to the CFS/ME Research Collaborative (CMRC)	Guideline	Rec 3.5	Suggest ‘orthostatic symptoms’ rather than ‘postural symptoms’.
UK Doctors Long COVID Group	Guideline	Rec 3.5	Who will be conducting the 10 minute stand test for POTS? This would take up a whole consultation in general practice or require a double appointment. Expertise is also required in interpreting the result.
Patient-Led Research for COVID-19	Guideline	Rec 3.5	We suggest modifying the text in parentheses to: "if you suspect postural tachycardia syndrome, or other forms of autonomic dysfunction" as patients in the Body Politic support group have been diagnosed with other forms of autonomic dysfunction. We also recommend evaluating for small fiber neuropathy as indicated (https://pubmed.ncbi.nlm.nih.gov/32984564/).
British Geriatric Society	Guideline	Rec 3.5	Please give parameters and protocols for the tests mentioned to make clear what is normal and abnormal, as knowledge about how to correctly carry out postural blood pressures may vary- there is a useful protocol in the POTS syndrome charity website.
Science for ME	Guideline	Rec 3.5	Use 'orthostatic intolerance' rather than 'Postural symptoms'; orthostatic intolerance is more widely used in post-viral syndrome literature. Add 'Be aware that orthostatic intolerance fluctuates substantially; a normal result from a standing test does not rule out orthostatic intolerance. Be guided more by reports of activities of daily life being affected by orthostatic intolerance'.

Stakeholder	Document	Section	Comments
UK Faculty of Public Health	Guideline	Rec 3.5	Page 6 line 18 and page 7 line 3) We wondered if the physiological tests referred to here needed more explanation for the normal GP who may not be familiar with them
University College London Hospital	Guideline	Rec 3.5	Autonomic dysfunction as a possible long-term effect of COVID 19 The nature of the autonomic dysfunction that may be one of the possible long-term effects of COVID-19 is not yet fully understood. The National Hospital for Neurology and Neurosurgery *NHNN) Autonomic Centre is a tertiary referral centre for Autonomic Disorders and has, over the years, seen many patients with a variety of post infectious autonomic disorders. These fall into a number of broad groups (please see below, under Indication*). It is important to make a distinction between those autonomic symptoms (which can occur non-specifically in the context of cardiovascular, respiratory, and musculoskeletal impairment) and those which occur in the context of documented autonomic dysfunction. In these cases, quantitative autonomic assessment is required to diagnose autonomic impairment, assess the severity of autonomic dysfunction, to plan tailored treatment and monitor response to treatment. Indication* The following autonomic disorders listed below may present either in the acute phase of the infection or form part of on-going symptomatology in any post COVID syndrome (or, conceivably, both) • New diagnosis of Postural Tachycardia Syndrome (PoTS) • Autoimmune autonomic disorder • New onset neurogenic Orthostatic Hypotension (OH) • New onset Autonomically Mediated Syncope (AMS, also known as vasovagal syncope) • Worsening of a pre-established autonomic disorder (for example, worsening of tachycardia in a patient with established PoTS, worsening of autonomic failure in a patient with a neurodegenerative autonomic disorders, autonomic neuropathy, or autoimmune autonomic disease. *These will need to be reviewed as more evidence becomes available Screening for autonomic dysfunction in Primary and Secondary care: Patients with cardiovascular autonomic dysfunction need not present with typical palpitation or light headedness on standing. Additional symptoms may therefore need to be considered. Patients with PoTS usually present with symptoms of orthostatic intolerance including lightheadness, dizziness, postural palpitations and with either syncope or presyncope. Additional frequent clinical features include fatigue, headache and a multi-visceral involvement, (Mathias CJ, Low DA, Iodice V, Owens AP, Kirbis M & Grahame R (2012). Postural tachycardia syndrome--current experience and concepts. Nat Rev Neurol 8, 22-34) In patients with neurogenic Orthostatic Hypotension (OH), hypoperfusion of organs, especially those above heart level such as the brain, cause the malaise, nausea, dizziness and visual disturbances that often precede loss of consciousness. A key component in the history is the relationship between symptoms and head-up postural change. Symptoms may be more prominent with rapid head-up change, for example, getting out of bed in the morning and on rising after a large meal, or after alcohol or exercise, (Mathias

Stakeholder	Document	Section	Comments
			CJ, Iodice V & Low D in Autonomic dysfunction: recognition, diagnosis, investigation, management, and autonomic neurorehabilitation. Handb Clin Neurol 110, 239-253) Screening tools for use at Primary and Secondary care could include the following: 1) A validated autonomic questionnaire, such as COMPASS 31; an appropriate tool to evaluate cardiovascular autonomic dysfunction. This questionnaire has been validated in a large cohort of patients with autonomic disorders (although further studies might needed for validation in patients with post COVID 19 syndrome). AIM: to assess for the presence of widespread autonomic symptoms of the kind that might reflect more widespread autonomic dysfunction. 2) Standing tests according to an autonomic protocol. Blood Pressure (BP) and Heart Rate (HR) to be measured with the subject lying supine at 1, 3 and 5 minutes. Five minutes of standing is then performed. Blood pressure and heart rate are recorded at 1, 3 and 5 minutes (Mathias C.J. LDA, Iodice V., Bannister R (2013). Investigation of autonomic disorders. In Autonomic Failure. A Textbook of Clinical Disorders of the Autonomic Nervous System, vol. Chapter 22. Oxford University Press). AIM: to document objective evidence of postural tachycardia, or orthostatic hypotension 3) If available (and in patients with autonomic symptoms and normal BP and HR response to standing tests) ambulatory 24 BP and HR monitoring is indicated. If obtained in association with diary it is often of help in diagnosing postural tachycardia, post prandial hypotension, orthostatic hypotension, exercise induced hypotension and supine hypertension. AIM: to document objective evidence of postural tachycardia, or orthostatic hypotension, exercise induced hypotension, supine hypertension, loss of circadian rhythm and features suggestive of autonomic failure. Referral to an Autonomic Service Early referral is needed in patients with autonomic dysfunction to avoid diagnostic delays and to put in place an appropriate management plan. The earlier patients with autonomic dysfunction are properly investigated and treated and the more effective is any autonomic rehabilitation (including the avoidance of deconditioning, the risk of falls or syncope and the development or worsening of anxiety and mental health problems). Early referral to an Autonomic Service is recommended for: 1) Patients with documented postural tachycardia who do not respond to non-pharmacological measures or anti hypotensive medication if indicated. Examples of patient pathway for postural tachycardia syndrome at Autonomic tertiary referral centre are described in following reference: A Tertiary Referral Centre for PoTS: The Autonomic Unit at the National Hospital for Neurology and Neurosurgery Experience. Valeria Iodice and Christopher J. Mathias. Postural Tachycardia Syndrome. In A Concise and Practical Guide to Management and Associated Conditions, pp 303-308. Springer. 2) Patients in whom there is a new diagnosis of Autonomic Mediated Syncope and who are not responding to non-pharmacological measures (or anti hypotensive medication if indicated) 3) Patients with a new diagnosis of neurogenic

Stakeholder	Document	Section	Comments
			Orthostatic Hypotension 4) Patients with pre-existing autonomic disorders who are experiencing worsening of symptoms and who do not improve after modification of therapy. Example of Autonomic Patient Pathways at the Autonomic Centre at NHNN are provided below: Diagnostic 1) Autonomic consultation 2) Autonomic screening tests (tilt table test, BP response to Valsalva manoeuvre, HR response to deep breathing, standing tests, ambulatory 24 BP monitoring, catecholamine supine and tilted). AIM: to diagnose and quantify autonomic dysfunction. 3) Additional autonomic testing , if required, and for indications as below a. Modified exercise test to assess exercise intolerance and exercise induced hypotension b. Liquid meal challenge test to assess post prandial hypotension and post prandial unmasking of postural tachycardia (including response to Octreotide, if needed) c. Dynamic sweat test and or thermoregulatory sweat test to assess neuropathic postural tachycardia, autonomic neuropathy Management 1) Consultant led Autonomic Multidisciplinary Team (MDT) Meeting to define treatment plan (tailored according to symptomatology, cardiovascular autonomic testing results and possible comorbidities and medication). 2) Syncope, Postural Tachycardia, Orthostatic Hypotension Management virtual clinic led by Clinical Specialist Nurses (including advice on autonomic rehabilitation). 3) GP Advice and Guidance service
Clinical Advisors to the Scottish Government (Clinical Guidance Cell, Professional Advisory Group)	Guideline	Rec 3.5	Again this is a time consuming suggestion that would not be suited to an average GP appointment. If it is an evidence based recommendation then some suggestion as to who has responsibility for this assessment should be given.
Long Covid Support Group	Guideline	Rec 3.5	10 minute stand test for PoTS needs to be during MDT assessment, and would need training to interpret. This would take up a whole consultation in general practice.
POTS UK	Guideline	Rec 3.5	PoTS UK are reassured to see the inclusion of screening for PoTS. We are aware of many diagnosed patients who believe that their symptoms have developed post covid-19. This inclusion will help steer patients to timely appropriate therapeutic interventions, and prevent psychiatric mis-diagnosis. We hope that screening will be embedded in the ongoing pathways for post-covid patients, and believe that autonomic specialists will be a critical to effective multi-specialty and multidisciplinary centres that evolve to meet the needs of patients.

Stakeholder	Document	Section	Comments
Forth Valley Patient Public Partnership	Guideline	Rec 3.6	Clear pathway
Lifestyle, Exercise and Nutrition Improvement (LENI) Research Group	Guideline	Rec 3.6	It would be important to clarify whether X-rays will be offered on one on multiple occasions.
Faculty of Health Sciences, Oxford Brookes University	Guideline	Rec 3.6	This recommendation should be reviewed. Unless you explicitly state what benefit a chest Xray is going to offer (i.e. what specific treatable condition is being looked for, or how will it help with prognosis?), the clinician will not know why they are doing it.
UK Doctors Long COVID Group	Guideline	Rec 3.6	A CXR is not sufficient to rule out significant lung pathology in people with ongoing breathlessness
Asthma UK/British Lung Foundation	Guideline	Rec 3.6	It would be helpful to clarify what results maybe expected from the chest x-ray and how this could contribute towards a long-covid diagnosis. We recommend that an algorithm be developed to show which tests should take place, when, and how this links to existing lung disease diagnostic pathways.
Royal College of General Practice England, Wales, Scotland and Ireland	Guideline	Rec 3.6	Can the committee clarify the CXR statement. If a patient has ongoing symptoms of a respiratory nature at 4 or 5 weeks and has not had one taken it is essential it is performed early to exclude cancer or ongoing pneumonia. By offering chest X-Ray 12 weeks after acute COVID-19 illness some pathology will be missed.

Stakeholder	Document	Section	Comments
British Geriatric Society	Guideline	Rec 3.6	Advising a chest XRay by 12 weeks seems very late given the drive not to miss lung cancers by attributing incorrectly to covid (it contradicts point 4.1 regarding ruling out red flags by 6 weeks).
Public Health Scotland	Guideline	Rec 3.6	Are convalescent films routinely recommended for all admitted patients- and at what time point – 6/52 or 3/12?
UK Faculty of Public Health	Guideline	Rec 3.6	Page 7 line 7. Should the possible additional tests beyond CXR be mentioned (eg spirometry?)
BAME Health Collaborative (BHC)	Guideline	Rec 3.6	3.6 Role of Imaging in COVID-19: Polymerase chain reaction (PCR) test can be initially negative in up to 30% cases of COVID-19; therefore, imaging plays a vital role in the management of patients. Chest Radiographs (X-rays) are performed when there is a high suspicion of COVID-19 or to exclude other pathologies. CT scans are useful for evaluation of complications such as pulmonary embolism. Imaging also plays a role in the follow up of patients for example, in the patients who develop pulmonary fibrosis after COVID-19 infection. Various NHS and Department of Health (DOH) reports have established that the BAME community has a higher incidence of COVID-19. NHS & care sector staff from BAME backgrounds have been affected worse than other ethnicities. Availability of PPE for the staff, especially in the imaging department had been a concern. Sanitisation of the imaging equipment in between the patients in a busy Radiology department is also one of the challenges.
Royal College of Nursing	Guideline	Rec 3.6	We are supportive of this recommendation as there are many people who will either have not been tested due to not been hospitalised or may have potentially tested false negative.
CDH UK - The Congenital Diaphragmatic Hernia Charity	Guideline	Rec 3.6	In patients with pre-existing respiratory conditions that are poorly understood for example, has a discussion taken place on how Clinicians can determine what is Covid-19 related and what is pre-existing related when analysing chest x-rays and referral for further tests. This may be particularly important for self management and for understanding the pathogenesis/development of both Covid and any pre-existing condition and also any ongoing research or research thereafter. This is also important in limiting the number of X-rays and other tests that a patient may be offered and that may impact on future health or outcomes. Would this be classed as a red flag for example?
Chronic Long Covid	Guideline	Rec 3.6	You need organ mri scans with ecgs, not xrays or ecgs alone. mri scans with contrast, scintigraphy and ct scans are required.
Clinical Advisors to the Scottish	Guideline	Rec 3.6	There is no plan for what to do with this result. It would be helpful to have a pathway here to define who requires further respiratory assessment more broadly and what that should look like given the

Stakeholder	Document	Section	Comments
Government (Clinical Guidance Cell, Professional Advisory Group)			current regional variations in service and waiting times across the UK. Reasonable if has ongoing or new symptoms.
Royal College of Occupational Therapists	Guideline	Rec 3.7	suggest additional points: • Social prescribing service if they have common mental health problems that could be improved by social support and contact with community services • Primary care occupational therapy if they have common mental health problems that could be improved by tailored support to engage in activities of daily living
Forth Valley Patient Public Partnership	Guideline	Rec 3.7	Variations may occur locally depending on capacity
Lifestyle, Exercise and Nutrition Improvement (LENI) Research Group	Guideline	Rec 3.7	Considering the stigma attached to psychological therapies, before a referral is made, it would probably be necessary to the screening to be completed by expert personnel.
Faculty of Health Sciences, Oxford Brookes University	Guideline	Rec 3.7	No comment
Polymyalgia Rheumatica and Giant Cell Arteritis Scotland	Guideline	Rec 3.7	Again, can therapies be provided at the time of need when therapists are in such short supply and waiting times already so long?

Stakeholder	Document	Section	Comments
(PMR-GCA Scotland)			
Chartered Society of Physiotherapy	Guideline	Rec 3.7	3.7: This should be broader than psychological therapies / psychiatric services. Different referral pathways need to be clearly defined with criteria for which pathway is most appropriate. Can this information be incorporated into a flowchart?
ICUsteps Peer Support Charity	Guideline	Rec 3.7	Charities such as ICUsteps are running online peer support groups for recovering ICU patients and relatives, including those recovering from Covid. Patients, even with significant anxiety, depression and post traumatic stress disorder symptoms, find reassurance in speaking to other people who have gone through the same thing.
Royal College of General Practice England, Wales, Scotland and Ireland	Guideline	Rec 3.7	Can the committee consider adding the inclusion of practice based psychological therapies such as in-practice counselling services or talking therapies which could be offered through federations or GP Networks. Not all patients will need to be referred outside of primary care. Can the committee also consider rewording the liaison psychiatry sentence. Many localities do not have access to a liaison psychiatry service, so this is impossible to achieve. Suggest "Refer following local pathways to psychiatric services, or liaison psychiatry if available.
Long Covid Wales	Guideline	Rec 3.7	Please see comments to section 3.2 – it is vital that the guidelines highlight the prevalence of psychiatric presentations that are of organic cause. The approach taken to new presentations of anxiety or mood disorders must be to treat all treatable physical aspects first and foremost. Providing psychological care by asking a patient to adopt to a changing physical situation that has not yet been properly treated is both illogical and poor medical care. It is key to remember that the vast majority of mental health complaints in Long COVID are a consequence of the illness, not the underlying reason. Furthermore, addressing aspects of chronic medical conditions – such as a secondary mental health issue – must be considered to be part of the rehabilitation process, which comes at a later stage, and not part of the initial assessment. In the event of a mental health issue being diagnosed this must not discriminate against management of physical signs and symptoms.
British Society of Rehabilitation Medicine (BSRM)	Guideline	Rec 3.7	We are not confident that these services exist everywhere, & where they do cannot offer a timely response. Experience from Major Trauma is that there are unacceptably long waiting times, which can be up to 1 year. A dedicated service is required so that patients can be evaluated & supported pro-actively

Stakeholder	Document	Section	Comments
UEA/Fifth Sense/The Norfolk Smell and Taste Clinic	Guideline	Rec 3.7	See British Rhinological Society guidelines
British Geriatric Society	Guideline	Rec 3.7	There is no advice about the safety of advocating exercise for depression/ anxiety and the use of antidepressant medications, which patients are likely to ask about, or which is antidepressant is preferable depending on other ongoing symptoms. Please clarify what is meant by “common” mental health symptoms and “complex physical and mental health”? Usually psychiatrists ask GPs to look after the physical aspects of a patient’s care, so it is not clear why this is included?
Oxford University Hospitals NHSFT	Guideline	Rec 3.7	common mental health symptoms is a vague and inaccurate term. Perhaps depression and anxiety of mild to moderate severity? Good to see liaison psychiatry for complex presentation - but should we emphasize joint management rather than referral?
Science for ME	Guideline	Rec 3.7	Add to the beginning of this paragraph: 'People experiencing significant post-Covid-19 symptoms are likely to be upset and worried; these natural responses are not mental illness. Empathetic care and practical assistance helps greatly to prevent the development of secondary mental illness.'
UK Faculty of Public Health	Guideline	Rec 3.7	Page 7 line 11. After line 111 we wondered if specific mention of IAPT (Long Term Conditions) services is required as more traditional psychological therapies services have long waiting lists and IAPT (LTC) may be a speedier and appropriate first step. Page 7 line 16. Before 3.8 we wondered if a specific section on cognitive assessment was required. Unless a primary care screening tool is suggested, the assessment may well fall to memory clinics or psychological services , both of which are often difficult to access with long waiting lists. A recommendation in the guidance would assist prioritisation for patients needing this aspect of assessment.
Long Covid SOS	Guideline	Rec 3.7	This should not be done if a person is showing normal emotional distress about their sickness. Anxiety can be a loaded term and has been overused in the context of Long Covid.
National Guideline Centre	Guideline	Rec 3.7	Recommendation 3.7 refers to anxiety and mood disorders. Those who have been in intensive care may be deeply traumatised by their experiences. Such distress may compound the psychological impact of ongoing physical limitations due to COVID-19. It is important to be aware that distress has been reported by people with ME/CFS who have felt they were being labelled as imagining or amplifying symptoms as “all in the mind”.

Stakeholder	Document	Section	Comments
Chest Heart & Stroke Scotland	Guideline	Rec 3.7	The guideline is clear in terms of psychological distress in those diagnosed with COVID-19, however a holistic assessment would consider the impact on the wider family/ friends. There is a need to recognise the potential for psychological distress in the family and the need to ensure appropriate support.
British Psychological Society	Guideline	Rec 3.7	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. Moreover, psychological therapy services, such as IAPT in England, are designed to provide evidence-based psychological therapies for specific mental health conditions. 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). 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). 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). 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
Clinical Advisors to the Scottish Government (Clinical Guidance Cell, Professional Advisory Group)	Guideline	Rec 3.7	The current national/local guidance appears variable and requires more underpinning evidence.

Managing the long-term effects of COVID-19

Targeted consultation on draft guideline

Comments table

26/11/2020-01/12/2020

Stakeholder	Document	Section	Comments
Long Covid Support Group	Guideline	Rec 3.7	Take into account that there also seems to be a physiological basis to some mental health symptoms, for example many members of our Long Covid Support Group report that the adrenal system/sympathetic nervous system seems to be activated on a prolonged basis. This can cause insomnia, cognitive impairment as well as feelings of anxiety.
Deaf Scotland	Guideline	Rec 3.7	Will referral agencies be accessible for those with communication/language barriers?
Forth Valley Patient Public Partnership	Guideline	Rec 3.8	Example of need for multidisciplinary approach
Faculty of Health Sciences, Oxford Brookes University	Guideline	Rec 3.8	At long last! This needs to be at the very beginning, on the grounds that most people will start at the beginning of these guidelines and read them until they run out of energy, and they may not reach this recommendation.
NICE GP Reference Panel	Guideline	Rec 3.8	Shoudn't this be your starting point for diagnosing post-covid symptoms? Shouldn't it be an equal consideration rather than 'do not discount' .
British Society for Rheumatology	Guideline	Rec 3.8	We would like to see this statement having more prominence earlier in the document to emphasise the need for consideration of other diagnoses given that post COVID-19 syndrome has no clear definition and multiple symptoms.
Long Covid Wales	Guideline	Rec 3.8	With this novel disease, practitioners should be aware of unusual and unexpected laboratory results, e.g. thyroid tests, and need to appreciate that this may be directly linked to Long COVID, so should seek help in interpretation from specialists in laboratory medicine. Likewise, laboratories and pathologists of all disciplines should be aware of Long COVID potentially affecting laboratory assays.
British Society of Rehabilitation Medicine (BSRM)	Guideline	Rec 3.8	You could refer back to 1.3, where it should be explicitly stated that other potential conditions must be excluded
Science for ME	Guideline	Rec 3.8	We support this recommendation.

Stakeholder	Document	Section	Comments
ME Action UK	Guideline	Rec 3.8	We agree with this recommendation as, anecdotally, we are hearing of people with other serious illnesses that are being misdiagnosed as long COVID, including cancer.
National Guideline Centre	Guideline	Rec 3.8	Recommendation 3.8 should be earlier in this section to maintain logical flow – probably as the new 3.2.
Clinical Effectiveness Southwark	Guideline	Rec 3.8	other diagnosis are mentioned in general terms. I think it would be worth mentioning PE/DVT specifically though.
West Yorkshire and Harrogate Health and Care Partnership	Guideline	Rec 3.8	Red flags need to be included in this recommendation
British Psychological Society	Guideline	Rec 3.8	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.
Clinical Advisors to the Scottish Government (Clinical Guidance Cell, Professional Advisory Group)	Guideline	Rec 3.8	As always in clinical practice.
National Institute for Health Research, Centre for	Guideline	Rec 3.9	Unclear what the criteria for referral to specialist or rehabiltation services are

Stakeholder	Document	Section	Comments
Engagement and Dissemination			
Forth Valley Patient Public Partnership	Guideline	Rec 3.9	Essential part of pathway
Faculty of Occupational Medicine	Guideline	Rec 3.9	These services are rarely available, so the recommendation is not practicable to implement
Faculty of Health Sciences, Oxford Brookes University	Guideline	Rec 3.9	This recommendation is grammatically incorrect. It is a command, but does not tell you what to do. Refer people to what? It obviously implies to a rehabilitation service, but it does not state so. Moreover, it gives no clue as to who might benefit, and although there are obviously not any evidence-based criteria, it could say something like "anyone who has persistent limitations 12 weeks after onset of Covid 19 on their ability to undertake daily activities that used to be unaffected prior to the illness should be referred for a rehabilitation assessment." I would argue that the referral should be much earlier than 12 weeks, but given the arbitrary limit of 12 weeks imposed within this guideline, I have left it at 12 weeks.
Cardiff and Vale UHB	Guideline	Rec 3.9	PAGE 7 Line 21-23 • Refer people who would benefit from specialist or rehabilitation care irrespective of whether they have had a positive SARS-CoV-2 test (PCR, 22 antigen or antibody). This requires re wording as the services for rehabilitation post COVID need to be focussed initially for those who have new symptoms that are related to COVID-19 commencing post March 20.It should not be expected for these services to provide for people with post viral or chronic fatigue pre 2020, as capacity and demand will be hard to predict and define.
Patient Advisory Group to the CFS/ME Research Collaborative (CMRC)	Guideline	Rec 3.9	Should patients who meet the diagnostic criteria for ME/CFS, and who do not have additional symptoms that are not part of the symptoms of ME/CFS, be referred to specialist ME/CFS services? Patients without a positive SARS-CoV-2 test are effectively indistinguishable from other ME/CFS patients. Should recommended care therefore be the same? If not, why not?

Stakeholder	Document	Section	Comments
UK Doctors Long COVID Group	Guideline	Rec 3.9	This statement is unclear and should be rephrased to state that the absence of a positive PCR/antigen/antibody test result is not a barrier to referral to the COVID MDT clinic or for further investigations/specialist input.
Asthma UK/British Lung Foundation	Guideline	Rec 3.9	It would be helpful to clarify the circumstances in which a person may benefit from specialist and rehabilitative care, and what type of rehabilitation this would be.
Chartered Society of Physiotherapy	Guideline	Rec 3.9	3.9: Specialist or rehabilitation care need to be defined.
Long Covid Wales	Guideline	Rec 3.9	It would be appropriate to highlight that a diagnosis of COVID-19 can equally be made by laboratory results or on clinical grounds; this statement should be made clearer.
UEA/Fifth Sense/The Norfolk Smell and Taste Clinic	Guideline	Rec 3.9	see www.fifthsense.org.uk for referral options for smell/taste dysfunction
British Geriatric Society	Guideline	Rec 3.9	This is a very important point, should it be earlier in this section? However it will be difficult to know whether the patients referred have indeed had covid without any test result in the absence of typical symptoms. I look forward to further research with a more precise means of making this distinction.
Science for ME	Guideline	Rec 3.9	We support this recommendation.
ME Action UK	Guideline	Rec 3.9	We strongly agree with this recommendation. It is vital that there is recognition that not everyone suffering with long COVID will have had a positive test.
Department of Health (Northern Ireland)	Guideline	Rec 3.9	The rationale section at the end of the document is helpful, but some of the points made very well there are perhaps less clearly worded in the main body of the text. For example, in the rationale section it states that absence of a positive PCR or antibody result should not mean that patients with symptoms cannot access the recommended services. This is mentioned in para 3.9 in relation to specialist referral, but that is quite late in the document and easily missed. This is an important point and would have more impact if mentioned earlier.

Stakeholder	Document	Section	Comments
British Psychological Society	Guideline	Rec 3.9	We agree. However, 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) We suggest the recommendation should be: "Follow relevant national or local guidelines on referral for people who have cognitive symptoms. Consider referral to clinical neuropsychology or specialist neurorehabilitation services."
Clinical Advisors to the Scottish Government (Clinical Guidance Cell, Professional Advisory Group)	Guideline	Rec 3.9	This adds nothing. It applies to any patient COVID or otherwise. It depends on whether there is a definite and separate COVID pathway which is not a recommendation in this guideline.
Association of British Neurologists	Guideline	Rec 3.9	concerned about the 'refer to rehabilitation services' that are already struggling, poorly resourced and suffer badly from postcode lottery syndrome under the current level 1, 2 and 3 rehab which is resourced separately to trusts and is hugely variable - Essex for instance has no Level 2 Rehab. At NHNN we only have Level 1 and locally only Level 3 - so a referral to rehab isn't going to happen for most as it doesn't exist!
Engender	Guideline	Rec 4.1	It is important to have multiple sources of information which have taken accessibility into account. Maintaining privacy must be a central consideration.
NICE GP Reference Panel	Guideline	Rec 4.1	What is the difference between the 'integrated multi-disciplinary assessment service' and 'specialist' from the primary care / GP perspective? Is there a new assessment service for this cohort, distinct to referral to Resp / Cardiology / Psych? If not, this should be deleted - it is a bit unclear There also needs to be greater mention of Occupational Health and how they will support people
Forth Valley Patient Public Partnership	Guideline	Rec 4.1	Inclusion of self management and continued dialogue essential element in this long term condition

Stakeholder	Document	Section	Comments
Lifestyle, Exercise and Nutrition Improvement (LENI) Research Group	Guideline	Rec 4.1	"Self management" should really be "self directed" and accompanied by a comprehensive pack of supporting information, literature and sources, which would go beyond simply pointing to a website. This should contain sufficient information for patients to refer to, according to their needs.
Faculty of Health Sciences, Oxford Brookes University	Guideline	Rec 4.1	This refers to "the holistic assessment". Is this referring to the assessment mentioned in 2.1? It is not clear how this holistic assessment is supposed to have occurred. Is this to be undertaken by the general practitioner? A multidisciplinary team? If this is occurring in the same interview as the original holistic assessment, which would seem sensible, then the total time involved is likely to extend to 40 minutes or more. Is this realistic? This recommendation also seems to override the logic of the 12 weeks in the definition because it is suggesting referral at six weeks. The whole guideline needs to be internally consistent in its use of times, definitions and so on.
Cardiff and Vale UHB	Guideline	Rec 4.1	advice on self-management, with the option of supported self-6 management This should (must) include use of digital resources eg. We have developed a rehabilitation web site for this very purpose www.keepingmewell.com
Patient Advisory Group to the CFS/ME Research Collaborative (CMRC)	Guideline	Rec 4.1	In cases where patients meet the diagnostic criteria for ME/CFS, and who do not have additional symptoms that are not part of the symptoms of ME/CFS, should these patients be referred to specialist ME/CFS services?
Carers Scotland	Guideline	Rec 4.1	We would suggest adding a recommendation to provide any carer with information on or referral to their local carers centre for support. Carers centres provide a wide range of support to carers including in many areas being the gateway to a carer's assessment as well as emotional support, assistance with getting a break from caring and income maximisation.
British Society for Rheumatology	Guideline	Rec 4.1	We have concerns that 'referral to an integrated multidisciplinary assessment service from 6 weeks once red flags have been ruled out' will overwhelm the system to the detriment of those very sick individuals (post-ITU) with significant rehab needs and chronic organ damage.

Stakeholder	Document	Section	Comments
Royal College of Physicians and Surgeons of Glasgow	Guideline	Rec 4.1	This recommendation may be challenging as services for post COVID syndrome will not currently exist in some areas, with the integrated team as described, especially where there is still uncertainty/lack of much robust evidence as to the best approach and outcomes. It is recognised this will evolve over time as more evidence becomes available.
The Poverty Alliance	Guideline	Rec 4.1	Shared decision making should recognize other support services the person can access beyond healthcare support such as welfare rights to support income maximization if required and other community support as applicable such a Links workers operating within Scottish GP Practices within areas of deprivation. This may also include advice or support for others within the household affected by the patients condition for example providing care .
Chartered Society of Physiotherapy	Guideline	Rec 4.1	1: Who will provide supported self-management? Is there a programme / resource that people should be directed to e.g. yourcovidrecovery. Line 11: Is the multidisciplinary clinic a COVID specific one? Why from 6 weeks?
ICUsteps Peer Support Charity	Guideline	Rec 4.1	A small number of ICUs are offering rehabilitation services including online exercise classes run by physiotherapists for post ICU patients including post Covid. In addition, Psychologists in Intensive Care (PINC-UK), affiliated to the Intensive Care Society (ICS) provide psychology services for post ICU patients including those recovering from Covid.
Royal College of General Practice England, Wales, Scotland and Ireland	Guideline	Rec 4.1	Can the committee consider adding the use of Social prescribers? Suggest adding “Consider referral for social support via the emerging network of Social prescribers” Note: 5.1 page 7 line 9-10 just mentions social prescribing as an activity only not a route of referral and primary care support The “integrated multidisciplinary assessment service” is recommended but not available in many areas including Scotland, Wales and Northern Ireland. Please ensure you put “if available” within this section. ‘Red flags’ are not truly defined in the document with the description on page 2 vague. Can the committee consider adding further explicit descriptions of red flags, either here or in the definition on page 2 to highlight the safety issues in ensuring alternative diagnosis such as cancer and heart failure are ruled out. further guidance is required here.
Long Covid Wales	Guideline	Rec 4.1	Clarification is needed regarding the timeline – is the referral to a multidisciplinary assessment service from 6 weeks after initially developing COVID-19?
British Society of Rehabilitation	Guideline	Rec 4.1	For those with cognitive deficits holistic assessment must be in association with family or care givers The last line should specifically state including specialist rehabilitation services when required

Stakeholder	Document	Section	Comments
Medicine (BSRM)			
British Geriatric Society	Guideline	Rec 4.1	Please make it clear that these will be dealt with in the next section or include a link to 5.1 section in case the clinician is dipping into the advice and does not realise it is further on in the guideline. “once red flags have been ruled out”- as mentioned previously, this contradicts “up to 12 weeks” for a chest X ray. Also, many time frames for 2 week wait referral regard certain symptoms lasting 4 weeks, which may be felt by the patient to be too soon to look for another cause after having been ill with covid, so they may not present or want onward 2 week wait referral at that time. By the time they manage to book another review appointment a couple of weeks later and attend a 2 week wait appointment with or without having been given another appointment for examination, another 4 weeks may have lapsed, plus a week or two before the letter gets back to the GP with the conclusion following 2 week wait investigation, then another appointment to review the patient’s symptoms to assess whether they need onward referral. This brings the time lapsed to 12 weeks after the acute symptoms. 6 weeks seems a bit optimistic by which to have excluded red flags.
The Royal College of Pathologists	Guideline	Rec 4.1	C/ Section 4.1: There is no mention of relevant websites and similar resources such as “Your Covid Recovery”.
Action for M.E.	Guideline	Rec 4.1	Patients should be given further information on shared decision making and patient choice. It must be clear that they can stop treatment/management at any point should they wish without it effecting the support on offer. The recommendations here feel deliberately vague which can open up patients to dangerous and harmful treatments through the interpretation on the ground. There needs to be more clarity on what should NOT be offered to people experiencing post-exertional malaise, such as graded exercise therapy.
Oxford University Hospitals NHS FT	Guideline	Rec 4.1	distinction and relationship between multidisciplinary assessment and multidisciplinary rehabilitation not clear
Public Health Scotland	Guideline	Rec 4.1	What is supported self management – is there standard advice on self-management being developed? When are the MDT assessment services being set up – and who is staffing them? What is ‘specialist care’ meant to mean – a dedicated COVID clinic??

Stakeholder	Document	Section	Comments
UK Faculty of Public Health	Guideline	Rec 4.1	Page 8 line 9. The current thresholds for secondary care mental health services accepting referrals is extremely high. It is possible that patient with these syndromes, however debilitating, may in some places, find it difficult to be 'taken on' by specialist services. Whilst this is not something for the guideline, it may be a 'consideration' for commissioners to address that should be explicitly stated somewhere. This would also apply to the availability of MDT services for these conditions (page 9 line 24)
Long Covid SOS	Guideline	Rec 4.1	Concern that if wait times are long for the multidisciplinary clinics patients may not be seen until they are 4 or 5 months post infection. Would welcome the option for earlier referral
Department of Health (Northern Ireland)	Guideline	Rec 4.1	Para 4.1 advises options, including referral to either an integrated primary care, community care, mental health team or an Integrated multidisciplinary assessment service from 6 weeks (once red flags are ruled out), with a one-stop clinic one option to deliver this. In the rationale section some more detail is provided on this, with suggested professional group input. However no referral criteria were able to be agreed because of the uncertainties already noted – and this leaves service planners in a nearly impossible position. Although the proposed approach is difficult to disagree with conceptually, without a broad estimate of patient numbers and the likelihood of attendance numbers in terms of new and review appointments needed, every commissioner and provider is at risk of reinventing the wheel.
West Yorkshire and Harrogate Health and Care Partnership	Guideline	Rec 4.1	There are some further types of support/rehab that could be included in this list. Peer support could be helpful for some people. The role of rehabilitation services needs to be mentioned in this list, with a stronger focus. It would be useful to include information on how decisions for referral should be made, baselines for referral to rehab. VCSE organisations could play an important role in supporting self management. Therefore working in partnership with local VCSE organisations needs to be included in this section. This could include specialist organisations to support population groups experiencing high impacts, e.g. women, people from minority ethnic communities. Broader support also needs to be included, e.g. occupational therapy, financial/housing support, , support for caring responsibilities etc.
Public Health England	Guideline	Rec 4.1	Line 9-10, P8 – 'Integrated and Coordinated' services, perhaps say 'where available'
British Psychological Society	Guideline	Rec 4.1	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. However, we suggest some it would be helpful to define what supported self-management might entail, and who will be providing support.

Managing the long-term effects of COVID-19
Targeted consultation on draft guideline
Comments table
26/11/2020-01/12/2020

Stakeholder	Document	Section	Comments
Scottish Intercollegiate Guidelines Network (SIGN) Council	Guideline	Rec 4.1	The opening paragraphs in this section should state the current knowledge about trajectory of symptoms. From the evidence reviewed, it suggests that many patients are still symptomatic at 4 weeks post infection, this decreases by 12 weeks and that it is unknown at present for how long a small proportion of patients will remain symptomatic. "This should include...." The evidence is not strong enough to state "should" replace with "could" Lines 9-13 - It is not clear from the evidence that support from integrated primary care, community care and mental health services nor that an integrated multidisciplinary team assessment in 6 weeks is the best option. I recognise this might be a view from the experts but this not based on evaluation of all options. The following is an option. Depending on clinical need patients may be managed by primary care practitioners with referral to specialist services as necessary.
Chronic Long Covid	Guideline	Rec 4.1	Stop the repackaging of cbt/get for what we now know is a physical post viral illness (with biomarkers showing that)
Mast Cell Action	Guideline	Rec 4.1	Greater consideration needs to be given to the less common long term symptoms, allergy and gastrointestinal symptoms in particular.
Clinical Advisors to the Scottish Government (Clinical Guidance Cell, Professional Advisory Group)	Guideline	Rec 4.1	Strongly agree with this especially given the lack of evidence base in doing other things at present. It should link to a self advice document here “AND” ??? suggests this is compulsory but then says "depending on clinical need". It could suggest that onward referral was always appropriate or beneficial. This needs to change as ambiguous. Yes. Realistic Medicine approach.
Long Covid Support Group	Guideline	Rec 4.1	Line 4: Include ‘diagnosis’ and ‘treatment’ between ‘assessment’ and ‘support and rehabilitation’. Line 6: When advising on self-management, include guidance for patients about resting, pacing and diet, since many people with Long Covid report that certain ingredients can exacerbate symptoms (alcohol, caffeine, refined sugar). Line 11: Why is referral to an integrated multidisciplinary assessment service suggested only from 6 weeks?
Neurological Alliance	Guideline	Rec 4.1	Suggest the inclusion of 'families + carers, as appropriate' here, in line with 1.1. Recommend the inclusion of "this should include: who to contact if they are concerned about new or continuing symptoms'; (also in line with 1.1)

Stakeholder	Document	Section	Comments
Forth Valley Patient Public Panel Partnership	Guideline	Rec 4.2	Consideration is given to the overall impact on life
Faculty of Occupational Medicine	Guideline	Rec 4.2	This should also include work
British Society for Rheumatology	Guideline	Rec 4.2	This will help to identify which is the most appropriate lead specialty – assessment and management that includes assessing respiratory capacity and general fitness indicates that these conditions' care should be driven by respiratory/acute-med or rehab physicians/geriatricians with general medical knowledge. Need to also consider how the offer will incorporate mental as well as physical health support.
Chartered Society of Physiotherapy	Guideline	Rec 4.2	4.2: Include identification of triggers/ precipitating factors to support identification of patterns / fluctuations in symptoms
British Geriatric Society	Guideline	Rec 4.2	"Different levels of support at different times"; much will depend on how quickly patients will be seen in the covid hubs after first referral and whether they will be able to self refer back into the service at a time when they will need and benefit from the service?
Science for ME	Guideline	Rec 4.2	It is vital that the possibility of Post-Exertional Malaise be considered, even if the person themselves may not identify it as such, given the potential of harm from over-exertion for people with this symptom (see draft ME/CFS guideline, https://www.nice.org.uk/guidance/gid-ng10091/documents/draft-guideline).
The Richmond Group of Charities	Guideline	Rec 4.2	Given that this cohort of individuals is likely to already experience long-term, often multiple conditions, the additional impact on people's lives of co- and multi-morbidities and their symptoms must be taken into account. Alongside this, the need to consider non-clinical needs such as an individual's physical, social, psychosocial and practical needs as well as their level of financial independence should be made explicit.
West Yorkshire and Harrogate Health and	Guideline	Rec 4.2	It is useful that the guideline includes a focus on shared decision making and working with the patient.

Stakeholder	Document	Section	Comments
Care Partnership			
British Psychological Society	Guideline	Rec 4.2	Agree
Clinical Advisors to the Scottish Government (Clinical Guidance Cell, Professional Advisory Group)	Guideline	Rec 4.2	This adds nothing and really would be considered by any healthcare professional. Agree strongly. However, the exact nature of ‘appropriate level of support ‘ is not very well defined. It is very likely that initial signposting to low tiered supportive provision of information in accessible format would be helpful for patients and their carers/family. This could be modified and tiered as more is known about symptoms/treatments that are effective.
Engender	Guideline	Rec 4.3	Must consider the timing and spacing of rehabilitation services to ensure no barriers to access for women, for example coinciding with school pick up, requiring significant travel etc.
Forth Valley Patient Public Partnership	Guideline	Rec 4.3	Again multidisciplinary approach which require time for co-ordination
Faculty of Health Sciences, Oxford Brookes University	Guideline	Rec 4.3	This is unhelpful. Anyone can consider anything at any time. To be useful, a guideline needs to make a recommendation that under circumstance A, then you are recommended to take action B. This does not preclude action B being taken for other reasons, nor does it preclude not undertaking action B. Simply stating that something should be considered is wasting a person's time reading that particular statement.
Cardiff and Vale UHB	Guideline	Rec 4.3	line 11 and 23 • referral to an integrated multidisciplinary assessment service from 6 weeks … and early referral. These 2 lines are not really saying the same thing. Referral to rehab if early referral needed may well be appropriate before 6/52
Polymyalgia Rheumatica and Giant Cell	Guideline	Rec 4.3	A multidisciplinary "one stop shop" is an excellent approach which would be much appreciated by those who are ill, elderly or otherwise disabled. It reduces the need to travel and the extended period that often occurs before multiple assessments can be obtained.

Stakeholder	Document	Section	Comments
Arteritis Scotland (PMR-GCA Scotland)			
UK Doctors Long COVID Group	Guideline	Rec 4.3	This section should include paragraphs on the treatment of symptoms, not just self-management or supported self-management and rehabilitation. It should be made explicit that underlying organ pathology will need specific treatment depending on the diagnosis, which should be managed by a relevant specialist via the Post COVID assessment clinic.
Chartered Society of Physiotherapy	Guideline	Rec 4.3	4.3: Should early referral be considered for all symptoms, not just for those that require MDT rehab
British Society of Rehabilitation Medicine (BSRM)	Guideline	Rec 4.3	This should read " person &/or family (for those unable to make informed decisions about their health or care requirements)". This recommendation should be robust, not merely a consideration. As soon as multidisciplinary rehabilitation is identified as a need or potential need, refer immediately.
UEA/Fifth Sense/The Norfolk Smell and Taste Clinic	Guideline	Rec 4.3	psychological and nutritional support may be needed for chemosensory loss
British Geriatric Society	Guideline	Rec 4.3	This may still take up to 12 weeks if red flags need to be excluded (see above), as referrals cannot be made in tandem.
Oxford University Hospitals NHS FT	Guideline	Rec 4.3	see comment on 4.1
British Psychological Society	Guideline	Rec 4.3	Agree

Stakeholder	Document	Section	Comments
Clinical Advisors to the Scottish Government (Clinical Guidance Cell, Professional Advisory Group)	Guideline	Rec 4.3	That's all very well but what will be available? Given most symptoms will improve over time and this will add to waiting lists and there is no evidence base I do not find this a helpful sentence unless there is a strong evidence base. Yes, although also cites delivered by near me technology in one paper which may reduce person resource requirement.(Salawu 2020).
National Voices	Guideline	Rec 4.3	We strongly support the focus on the impact of symptoms, rather than necessarily biological markers, in this part, and throughout the whole guideline. This is again, progressive, and very welcome, because it enables a more equal conversation where the patient can be an expert in the impacts and what seems to trigger a worsening or what seems to help. It also turns the attention to practical sources of help, such as emotional support, practical support or help with remaining or becoming physically active. We are also pleased to see a recognition that impacts can fluctuate, and that therefore support needs to be tailored and remain open ended. We know from years of experience, particularly around mental health, that it is extremely unhelpful and counter productive to discharge people as soon as they recover somewhat – the anxiety of losing the open door of an ongoing service means people can be forced into emphasising the deficits, rather than the assets in their lives. We hope that we won’t make these mistakes here, with people constantly being discharged, as soon as the slightest improvement occurs, only to have to start queuing again for access if a symptom flares up or returns.
National Institute for Health Research, Centre for Engagement and Dissemination	Guideline	Rec 5.1	Drawing on the experience of managing long term conditions, helping people to develop effective self managment strategies can be enanced by use of specialist nurse services or District Nursing services
NICE GP Reference Panel	Guideline	Rec 5.1	How do people receive employment advice - we need to explicitly mention Occupational Health somewhere in this document, whether this is via the employer or GPs filling in Med3 notes with greater consideration to workplace adaptions and adjustments to enable people to maximise their functional

Stakeholder	Document	Section	Comments
			ability. Given home working, the options have to be greater than 'fit' or 'not fit' and expertise should be sought from Occupational Health teams where required.
Forth Valley Patient Public Partnership	Guideline	Rec 5.1	Reiterates some earlier points but give vital working out of it I.e.who to contact and sources of advice and support Consideration of patient groups and third sector involvement in the community could be included
Lifestyle, Exercise and Nutrition Improvement (LENI) Research Group	Guideline	Rec 5.1	The way this section is constructed makes it too simplistic and not very helpful as it the majority of the aspects covered are dictated by common sense and logic, lacking the novelty and detail that someone with long COVID-19 would expect to receive from a healthcare profesisonal.
Faculty of Health Sciences, Oxford Brookes University	Guideline	Rec 5.1	Precisely where is someone going to get advice about financial support from? Services have been cut so much that it is extremely difficult to obtain this from any free source. Furthermore, given that the majority of people with this problem will be relatively old, have limited abilities to get into the community, and have less access to the Internet than most, this is only helpful if more advice is made available about how this is to be achieved.
Cardiff and Vale UHB	Guideline	Rec 5.1	Again should emphasise the need to deploy digital resources as a first line
Patient Advisory Group to the CFS/ME Research Collaborative (CMRC)	Guideline	Rec 5.1	Patients who meet the diagnostic criteria for ME/CFS, and who do not have additional symptoms that are not part of the symptoms of ME/CFS, should be advised to pace themselves, keeping their activity levels to within their energy envelope (see draft ME/CFS guidelines). Based on the experiences of ME/CFS patients, goals outside of a patient’s energy envelope may be detrimental. The draft ME/CFS NICE guidelines recommend against the use of ‘any programme based on fixed incremental increases in physical activity or exercise, for example graded exercise therapy’ yet these guidelines direct patients to ‘Your COVID Recovery’ site which under ‘Getting Moving Again’ advises increasing amounts of exercise. ME/CFS patients have repeatedly reported harm from this approach. Similar harm is probable in post-COVID-19 patients who meet the diagnostic criteria for ME/CFS. If these patients have ME/CFS, permanent deterioration in health and ability may result. Patients who meet the

Stakeholder	Document	Section	Comments
			diagnostic criteria for ME/CFS would benefit from information about ME/CFS support groups and charities.
The ME Association	Guideline	Rec 5.1	This whole section is inadequate We can understand why symptoms relating to end organ damage involving heart, lungs etc are being referred to other sources of information and guidance on their management But why is there no basic information on the management of the main post viral symptoms, activity and energy management in particular, that are associated with COVID: Activity induced fatigue Cognitive dysfunction Dysautonomia Headaches Sleep disturbance Post exertional malaise Especially when guidance on these symptoms is contained in the new (draft) ME/CFS guidance We are particularly concerned about the emphasis on the use of the terms rehabilitation and goal setting at whatever stage a person is at in their Long COVID journey. There is no reference to the importance of rest, convalescence and pacing physical and mental activities when it becomes apparent that a person is not recovering from a COVID infection after a few weeks. Experience of dealing with people who have PVFS indicates that appropriate advice on activity and energy management during the very early stages (ie weeks) following the triggering infection can have a very beneficial effect on outcome. We are hearing from people with Long/post COVID who have relapsed as a result of returning to exercise too early on or trying to do too much and not keeping within their energy envelope. Why is there no reference to the warning that NICE issued in July in relation to the use of graded exercise therapy? https://meassociation.org.uk/2020/07/clinicians-letter-to-nice-results-in-statement-on-graded-exercise-for-post-covid-syndrome/?fbclid=IwAR17fsf21BQybsfcch8g5GzsUhAqtNjKoDktinJq-TaNzkpqFmrLhSRpCh4
Carers Scotland	Guideline	Rec 5.1	Again, we would suggest an additional recommendation to provide information to carers on getting support for themselves in their caring role. This in general would be a local carers centre which in most areas is the first step to getting a carer's assessment and can assist with emotional and practical support in caring.
UK Doctors Long COVID Group	Guideline	Rec 5.1	There is no mention of pacing, using the term ‘pacing’ will help patients and healthcare workers alike to identify relevant information on the subject and learn ? Advice is also needed on how patients can recondition themselves such as exercises to strengthen muscle themselves at home after a period of deconditioning ? Self-management needs to be a form of ‘supported self-management’ to ensure the patient gains maximum benefit
The Poverty Alliance	Guideline	Rec 5.1	Information needs to be available in multiple formats due to issues of digital exclusion or other barriers such as limited digital access within rural areas. Self management information also needs be

Stakeholder	Document	Section	Comments
			communicated in accessible formats to assist understanding. Information should also be provided that patients can share with their employers if appropriate.
NICE GP Reference Panel	Guideline	Rec 5.1	This is going to a crucial section of the guideline. I appreciate that the panel have made recommendations about service provision and multi-disciplinary clinics to be set up, but the reality is that this is likely to be many months and quite likely years before many parts of the UK will have access to these clinics. Thus the burden as always falls on General Practice so we need as many resources as we can to help guide our patients in self management as we are unlikely to have access to the specialist resources you mention in the guideline. Please can the panel find as many resources for GPs to use to help guide patients. There would be merit in a separate 'self management' section with a resource list of all the options available. For example yourcovidrecovery (which is already in the guide), the info from RCOT on recovery from post viral fatigue -https://www.rcot.co.uk/recovering-covid-19-post-viral-fatigue-and-conserving-energy
Asthma UK/British Lung Foundation	Guideline	Rec 5.1	The British Lung Foundation will soon be hosting health advice and information on managing and recovering from long-covid. We would be pleased if this could be signposted to people experiencing symptoms.
Chartered Society of Physiotherapy	Guideline	Rec 5.1	5.1: Line 6 – alter to person centred goals? Lines 9-11: suggest this is expanded to include supported self-management section of yourcovidrecovery. .
Royal College of General Practice England, Wales, Scotland and Ireland	Guideline	Rec 5.1	Can the committee consider adding exercise advice to this recommendation. There will be many patients in primary care that do not need referral to a specialist assessment clinic and the guidance does not give any advice on managing these patients in primary care without rehab intervention. Setting realistic goals does not cover when to start to exercise or how much to do. Is this covered in the Your Covid recovery website? If so, can it be added.
Long Covid Wales	Guideline	Rec 5.1	As a general comment to section 5, this is lacking a sub-heading for the treatment of symptoms (not just self-management). For example, beta blockers have been used with good effect in many suffering from tachycardia on minimal exertion; similarly have H1-blockers for those with symptoms strongly suggestive of MCAS; as well as colchicine for chest pain related to pericarditis. If these are not appropriate to be prescribed on a primary care level, this should be seen as a clear indication for

Stakeholder	Document	Section	Comments
			referral. As these guidelines continue to evolve, it would also be appropriate to include a sub-heading discussing the COVID vaccine and whether it is safe for a patient with Long COVID to receive it. Of course, it is likely that research into this will need to be performed. Regarding 5.1, this should also include advice regarding pacing, which is widely seen as one of the core management approaches for Long COVID. Explanatory notes should be added regarding post-exertional malaise, clarifying how – for those patients who experience this – activity will have a delayed impact ranging from a day to as far as several weeks.
UEA/Fifth Sense/The Norfolk Smell and Taste Clinic	Guideline	Rec 5.1	see above - Fifth Sense
Patient-Led Research for COVID-19	Guideline	Rec 5.1	We recommend adding the following as a bullet point: “instructions on pacing (https://www.rcot.co.uk/file/6696/download?token=XiA9qFCs) and self-management of post-exertion malaise.” On line 13 we recommend changing “and advice about financial support” to “as well as referrals for financial support and disability benefits like Personal Independence Payment (PIP)” to ensure that both doctors and patients are aware of disability benefits.
Action for M.E.	Guideline	Rec 5.1	The phrase 'realistic goals' gives the impression that for every person they should be aiming to increase activity and ability and push themselves to achieve this. For many they need to understand that they need to stop and wait for an improvement before trying to do more. 'Pacing' should be an encouraged technique whereby a patient plans their daily activity levels to stay within an 'energy envelope' which is the limit they can achieve before symptoms are exacerbated.
Patient Safety Learning	Guideline	Rec 5.1	As currently written the guidance does not mention the tailored programme of support that is being rolled out via the Your COVID Recovery phase 2. GPs need to be able to find out more about this service and how their patients can access it, if appropriate. GPs are undergoing specific training so that they understand the referral process to this support system. There needs to be patient facing communication on the design and availability of the Your COVID Recovery programmes of support.
Public Health Scotland	Guideline	Rec 5.1	‘Advice on social care, housing and employment’ – that is a bit outwith the remit of most physicians – needs to be better linked to other services – which would need a dedicated COVID service of their own Where is the ‘advice on new symptoms of COVID’ that they can share? The impact of post COVID

Stakeholder	Document	Section	Comments
			syndrome on work/finances/caring responsibilities may be significant. People will need advice on these areas and be supported to access relevant services, if they are available.
Science for ME	Guideline	Rec 5.1	The guideline says that advice should be given at the first assessment appointment. Given that there will be blood tests and other investigations that take time, the person will still only have a suspected Covid-related condition at this time. Therefore, the person should be referred to as 'a person with ongoing or new symptoms following a Covid-19 infection'. Re setting realistic goals. There is no guidance on what goals might be realistic. Many people with Long Covid report that goals with an aim of increasing physical or cognitive activity, or aiming to get back to work are counter-productive; they do not hasten recovery. This is in accord with the experience of people suffering from a range of post-infectious syndromes following other infections (i.e. subsets of ME/CFS). Numerous studies attempting to gradually increase physical activity in these patient groups have found that such approaches do not work. References to goals should be removed and replaced with advice relating to paying attention to symptoms and symptom-contingent pacing. We support the mention of support groups and online forums - these are very important for the well-being of many people with post-infection syndromes. We strongly support the guidance to get support, including financial support. We are concerned about the mention of the 'Your Recovery' page which includes advice such as 'The more time spent being physically active, the greater the health benefits'. This is not true, even for healthy people. There is no evidence that physical activity improves symptoms or hastens recovery in post-viral fatigue syndromes. The new NICE ME/CFS Guideline has recognised this. While studies have found that most people with post-infection syndromes at 3 months do recover, a significant proportion are still ill years and decades later. While we don't know yet what the prognosis is for people with Long Covid, the experience with SARS and MERS provides further grounds for expecting that some people with Long Covid will be disabled for life unless treatments are found. This possibility should be recognised in information for patients and their families.
Long Covid SOS	Guideline	Rec 5.1	Advice on pacing rather than goal setting is more appropriate. Do not want to set patients up for failure and life can't always be planned. Your Covid recovery contains advice about building strength and activity levels and this could actually be dangerous for some people with Long Covid, especially those with relapsing/remitting symptoms and post exertional malaise.
ME Action UK	Guideline	Rec 5.1	“Setting realistic goals” - using the word “goals” suggests that a) there is a known trajectory of improvement which can be mapped out and b) that the clinician and the patient will have enough knowledge to assess a realistic pathway. Since post-COVID-19 is a newly emerging syndrome, there is not evidence to support these assumptions. Moreover, evidence does suggest that those with post-

Stakeholder	Document	Section	Comments
			exertional symptom exacerbation/post-exertional malaise (PESE/PEM), may well get the best recovery through rest and recuperation. See Work Rehabilitation and Medical Retirement for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Patients. A Review and Appraisal of Diagnostic Strategies https://doi.org/10.3390/diagnostics9040124 “Patients who are given a period of enforced rest from the onset, have the best prognosis.” Secondly, the section of ‘Your Covid Recovery’ on ‘Getting Moving Again’ gives advice that is contraindicated in those with or developing ME yet there is no mention of the possibility of COVID-19 triggering ME. This means that patients are not being given the information they require to make informed decisions about their care. Where post-exertional symptom exacerbation/post-exertional malaise (PESE/PEM) is present, the evidence demonstrating worsening of symptoms after exercise programmes must be clearly stated. The draft ME/CFS guideline now explicitly says “Do not offer generalised physical activity or exercise programmes – this includes programmes developed for healthy people or people with other illnesses” and “Do not advise people with ME/CFS [...] to go to the gym or exercise more, because this may worsen their symptoms.” We propose changing this bullet point to “sources of advice and support tailored to the person’s symptom presentation, including support groups, social prescribing, online forums and apps.”
National Guideline Centre	Guideline	Rec 5.1	Recommendation 5.1 suggests setting realistic goals, but little about how this is to be done or determined. People with ME/CFS describe the need to set goals within their energy envelope. There is concern that patients may push themselves hard because of financial pressure or pressure from employment, particularly when they have dependents. This could be harmful to long term recovery.
Royal College of Nursing	Guideline	Rec 5.1	It would be good to have a link on the NHS and COVID apps in this section.
West Yorkshire and Harrogate Health and Care Partnership	Guideline	Rec 5.1	The role of the VCSE sector in supporting self management could be clearer here.
Public Health England	Guideline	Rec 5.1	5.1 management advice ways to self-manage – suggest as well as setting realistic goals, the 3 Ps are included here – pace, plan and prioritise (as per on the NHS COVID recovery website) Line 18-19, P9 – Please link to national Vitamin D guidelines In general re management – include smoking

Stakeholder	Document	Section	Comments
			cessation/alcohol/healthy eating advice and referral to existing smoking cessation, alcohol and weight management services (general opportunity for prevention messages)
British Psychological Society	Guideline	Rec 5.1	Overall, we agree with the recommendation for supported self-management. 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. 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. Psychological components of self-management would include • Managing anxiety • Managing traumatic stress symptoms • Managing mood and frustration • 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) 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.
Scottish Intercollegiate Guidelines Network (SIGN) Council	Guideline	Rec 5.1	For section 5.1, bullet point 3, community pharmacy could be referred to for advice and support. Explain to people that the natural history of this syndrome is as yet not fully elucidated and to date many people have symptoms at 4 weeks, with fewer at 12 weeks but it remains unknown how long some people will continue to have symptoms.
Clinical Advisors to the Scottish Government (Clinical Guidance Cell, Professional Advisory Group)	Guideline	Rec 5.1	This is the main section in this guideline given the lack of evidence base at this stage I would state this in the guideline more clearly. The statements are slightly bland and unhelpful to a healthcare professional. Who do patients contact for support? What info do they “share with their family”? Yes.

Stakeholder	Document	Section	Comments
Long Covid Support Group	Guideline	Rec 5.1	There are treatments for symptoms (cardiac, autonomic, neurological, for GI disturbance, nutrition) which are not mentioned. Also include mention of factors such as rest, pacing, dietary changes (eliminating alcohol, caffeine, refined sugar) to avoid exacerbating symptoms. Line 6: Replace ‘goals’ with ‘expectations’. Using language such as ‘goals’ risks people pushing themselves (potentially triggering worsening of symptoms) and also feeling a failure if goals are not achieved. Line 11: Be mindful when directing patients to the NHS Your Covid Recovery website that people experiencing difficulties with cognition (concentration, absorbing information) may struggle to read large sections of on-screen information. There may be other barriers to accessing the information (hardware/connectivity/language/hidden disabilities).
Royal College of Speech and Language Therapists (RCSLT)	Guideline	Rec 5.1	We suggest adding that information and advice must be tailored as not everyone will want everything at once as this can be overwhelming. Furthermore all information must be accessible, avoiding complex language and thus recognising people’s level of health literacy. Please see RCSLT guidance around Inclusive Communication.
Deaf Scotland	Guideline	Rec 5.1	How accessible will referral on be?
National Voices	Guideline	Rec 5.1	We are supportive of the emphasis on supported self-management. It is important not to confuse self-management with an absence of support from statutory or VCSE services. It is good to see that support groups and social prescribing are mentioned.
Forth Valley Patient Public Partnership	Guideline	Rec 5.2	Responsibility to share this valued
British Geriatric Society	Guideline	Rec 5.2	This is very welcome specific advice. A link to the national guidelines referred to about vitamin D would be useful.
The Society and College of Radiographers	Guideline	Rec 5.2	P9 line 19 What are the national guidelines on Vitamin D? Is there a reference for the guidance?
BAME Health Collaborative (BHC)	Guideline	Rec 5.2	5.2 Follow national guidelines in consultation with GP or other specialist consultant/team for those with other medical conditions and where there are concerns about contraindications with prescribed medication. Include a link for Vitamin D usage

Stakeholder	Document	Section	Comments
Royal College of Nursing	Guideline	Rec 5.2	There is no reference to free daily vitamin D supplements if one is at high risk (clinically extremely vulnerable) from coronavirus (COVID-19)
Scottish Intercollegiate Guidelines Network (SIGN) Council	Guideline	Rec 5.2	Explain to people that the natural history of this syndrome is as yet not fully elucidated
Clinical Advisors to the Scottish Government (Clinical Guidance Cell, Professional Advisory Group)	Guideline	Rec 5.2	The language here is unhelpful for a professional guideline. I would state the lack of evidence but the discussion with the patient around this may or may not be relevant. Need to point out here the contraindications for Vit D?
Long Covid Support Group	Guideline	Rec 5.2	Clinicians should ask patients what home/complementary/non pharmaceutical remedies they may be using, to learn of potential benefits and/or warn of potential interactions with other treatments. Do national guidelines on Vitamin D make reference to black and ethnic minorities with darker skin?
Advisory Committee on Antimicrobial Prescribing, Resistance and Healthcare Associated Infection (APRHAI)	Guideline	Rec 5.2	Recommendation needs to be consistent with the COVID-19 Vitamin D Rapid Review. Although there is insufficient quality of evidence for a more targeted recommendation, there needs to be strong encouragement to fulfil current recommended Vitamin D daily intakes.

Stakeholder	Document	Section	Comments
Royal College of Occupational Therapists	Guideline	Rec 5.3	Request occupational therapy referral through employer's occupational health scheme. Royal College of occupational Therapists can supply examples of developments within occupational health services eg Occupational therapy, Occupational Health, Kings College Hospital. Levels of complexity: Complex, moderate, mild long covid symptoms . Therapy Delivery: - Initial assessment - One off work-place visit (as needed) - Then follow up approximately every 2 weeks for up to 5 additional sessions. - This was mostly delivered virtually or over the telephone. Sessions focused on: Long COVID education (using the research and the resources that are currently available) Personalised goal setting using a motivational interviewing style of dialogue to support patients. Sleep hygiene Keeping activity diaries Fatigue management, pacing Finding the new normal Movement/gentle activity programs Advanced WSV, reports, case management Outcomes: Average 20-30% improvement in Fatigue Severity Scale , GAD-7 Anxiety, Patient Health Questionnaire 9 and Canadian Occupational Performance Measure scores (performance and satisfaction). In the complex category group – all are still off work. In the moderate and mild all are working with no sickness absences in last 1month.
Forth Valley Patient Public Partnership	Guideline	Rec 5.3	A little more on the how(especially in these days of added economic pressures) Could be considered
Faculty of Occupational Medicine	Guideline	Rec 5.3	Approximately 50% of workers in the UK have access to occupational health support. The recommendation should include ' where the patient is off work due to their symptoms, they should be encouraged to seek advice from their occupational health service (if they have access to one) .
UK Doctors Long COVID Group	Guideline	Rec 5.3	Where available patients should be advised to obtain an occupational health assessment to assist with the complexities of return to work. Consider including the Faculty of Occupational Medicine in the expert guidance.
Asthma UK/British Lung Foundation	Guideline	Rec 5.3	People who may have long-covid should also be advised on routes to take if there is a dispute with their employer, such as support from trade unions.
Chartered Society of Physiotherapy	Guideline	Rec 5.3	5.3: What is meant by ‘support’ and who should provide this? Any HCP?

Stakeholder	Document	Section	Comments
Long Covid Wales	Guideline	Rec 5.3	Extended phased returns to employment are most important, given the often chronic relapsing nature of Long COVID, and this should be explained to employers, including that an individual’s capacity may vary irregularly, e.g. day by day.
Patient-Led Research for COVID-19	Guideline	Rec 5.3	We recommend adding on line 21 to support patients in asking for accommodations at work by providing a doctor’s note to the employer.
British Geriatric Society	Guideline	Rec 5.3	Again a link to national guidance would be welcome. The guidance states that therapists can issue fit notes, which is not widely known about to my knowledge and may relieve the pressures on general practice in the same way as 111 have been able to issue sick notes online.
Action for M.E.	Guideline	Rec 5.3	The current recommendation indicates that a return to work can be instant. It needs to be clear that this should only be attempted when physically able to do so without worsening symptoms.
Public Health Scotland	Guideline	Rec 5.3	Occupational health are best placed to comment on this
National Guideline Centre	Guideline	Rec 5.3	External pressures on people to return to work should be referred to as anecdotally it seems that a phased return to work may be difficult to achieve for some people. More should be done to determine if early return to work and/or other activities can lead to deterioration, as has been described in ME/CFS, before this recommendation can be made without qualification.
Royal College of Nursing	Guideline	Rec 5.3	Consider adding: Risk assessment where appropriate/ relevant
West Yorkshire and Harrogate Health and Care Partnership	Guideline	Rec 5.3	The sentence “for advice on returning to work, follow national guidance” is a bit unclear and needs a link to more specific information. Many people have found the return to work difficult, given lack of recognition of their condition and the fluctuating nature of symptoms. Peer support could be included here It would be useful to make reference to the interactive/referral section on your covid recovery website.
British Psychological Society	Guideline	Rec 5.3	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. It may also be helpful to state that the NHS Your COVID Recovery website includes a page with advice on return to work.

Stakeholder	Document	Section	Comments
Clinical Advisors to the Scottish Government (Clinical Guidance Cell, Professional Advisory Group)	Guideline	Rec 5.3	If meant for GPs then they would be following existing guidance and COVID or otherwise will not affect this. I would take the first sentence out.
Long Covid Support Group	Guideline	Rec 5.3	Have the Faculty of Occupational Medicine been consulted by NICE? What specifically is the National Guidance on returning to work? Please reference this. People who have been absent from work for several weeks or more need individualised return to work plans, given the complexity and variety of health problems they experience. People in our Long Covid Support Group are highly motivated to return to work and need support in this.
Deaf Scotland	Guideline	Rec 5.3	Specific strategies regarding advice for Access to Work/other supports to consider reasonable adjustments, digital solutions, working from home etc?
National Institute for Health Research, Centre for Engagement and Dissemination	Guideline	Rec 5.4	Unclear why community nursing has not been included here
Forth Valley Patient Public Partnership	Guideline	Rec 5.4	Useful and adding value to partnership working
Faculty of Health Sciences, Oxford	Guideline	Rec 5.4	The first sentence in this recommendation is incomplete, and it is not clear who it is directed at. The clinician basing their assessment of the person on this guideline would not presumably have to assess the person again. It seems unnecessary to tell an integrated multidisciplinary rehabilitation service that they need to assess someone. It is equivalent to telling a service dealing with acute trauma that they

Stakeholder	Document	Section	Comments
Brookes University			need to make a diagnosis on the patient. Either this recommendation needs to be removed, or it needs to be made targeted at the audience it is intended for and to be written in a grammatically correct way.
UK Doctors Long COVID Group	Guideline	Rec 5.4	Please state the multidisciplinary rehabilitation team should include speech and language therapy due to reports of vocal cord dysfunction and prolonged hoarseness of voice.
Asthma UK/British Lung Foundation	Guideline	Rec 5.4	The draft guideline does not mention the digital rehabilitation component of the Your Covid recovery website. It should be made clear at what point a referral to this will be offered.
Chartered Society of Physiotherapy	Guideline	Rec 5.4	5.4: Is this a repeat assessment? Have they only been screened previously for onward referral? How is this joined up to previous assessments / investigations linked to referral?
British Society of Rehabilitation Medicine (BSRM)	Guideline	Rec 5.4	In this context, given potential multi-system involvement, there should be multi-disciplinary & multi-professional (ie: relevant specialities such as respiratory medicine, cardiology etc as well as Rehabilitation Medicine). Although many patients will be well managed by AHP led rehabilitation services, there will be a significant number with complex multi-dimensional needs where the skills of a Consultant in Rehabilitation Medicine, working with the MDT, will be essential. For patients needing MDT rehabilitation Rehabilitation Medicine should be involved in MDTs so that those complex problems which may not be recognised by AHP members of the MDT, will be identified. Rehabilitation Medicine can also organise relevent referrals, investigations & interventions, which AHP members may not be able to do.
Patient-Led Research for COVID-19	Guideline	Rec 5.4	On line 25, we recommend changing “psychiatric” to “neuropsychiatric.”
British Geriatric Society	Guideline	Rec 5.4	“Ensure that any symptoms that could affect the person’s safety to start rehabilitation have been investigated first”. This is not something GPs are trained in and may delay the start of rehab if patients are referred back to GPs. Is there advice which could be included in this part of the guideline to help the GP know if anything needs to be addressed before making the referral?
Action for M.E.	Guideline	Rec 5.4	This gives the impression that a form of CBT based on deconditioning would be helpful to people experiencing post-Covid illnesses. This can be harmful to those experiencing post-exertional malaise

Stakeholder	Document	Section	Comments
			and also emphasises the disbelief and misunderstanding into their condition. This is why it is essential that those fitting the diagnostic criteria for M.E./CFS are referred to the relevant guideline.
Oxford University Hospitals NHS FT	Guideline	Rec 5.4	see previous comment about relationship between assessment service and rehab service
Patient Safety Learning	Guideline	Rec 5.4	Earlier, the list includes 'cognitive' aspects, this should also be included here for consistency and clarity.
Public Health Scotland	Guideline	Rec 5.4	Rehab medicine should be commenting on the feasibility of this.
Science for ME	Guideline	Rec 5.4	Add 'A subset of people with post-COVID-19 symptoms may have ME/CFS. For them, any programmes promoting increases in exercise despite worsening symptoms could be harmful. It is therefore imperative that all staff in these clinics are aware of the new draft Guideline on ME/CFS. https://www.nice.org.uk/guidance/indevelopment/gid-ng10091/consultation/html-content-2.'
National Guideline Centre	Guideline	Rec 5.4	In recommendation 5.4 the phrase "psychiatric aspects of rehabilitation "should be deleted. The way this is currently written implies that post COVID-19 patients have a psychiatric illness. This is likely to be viewed as offensive and without an evidence base. Its implications conflict with the recommendations in the ME/CFS guideline. The sentence 'Ensure that any symptoms that could affect the person's safety to start rehabilitation have been investigated first' is important and should be a separate recommendation. We also suggest these edits- 'Ensure any symptoms that could affect the person's safety to start rehabilitation have been investigated before starting a programme of rehabilitation.'
The Richmond Group of Charities	Guideline	Rec 5.4	The highlighting of the importance of non-clinical needs such as seeking out employment and housing support, as referenced in Section 5.1 ("Self-management and Supported self-management"), is welcomed. However, assessing non-clinical needs is also vital in the development of personalised rehabilitation and management plans and therefore should be made explicit in the section on 'Multidisciplinary Rehabilitation'.
West Yorkshire and Harrogate Health and	Guideline	Rec 5.4	It is useful that this section focuses on multidisciplinary rehab, with a focus on the broad spectrum of patient needs. Some information on timing would be useful – there is evidence that quicker rehab prescriptions are more beneficial for patients. Social prescribing is mentioned in a list, but there could be a stronger focus, including more information on the types of social prescribing that could be

Stakeholder	Document	Section	Comments
Care Partnership			integrated. It is important to include social aspects of rehabilitation, e.g. employment, social role e.g. caring responsibilities. It is unclear what role local authority services can play, e.g. reablement services, community activators.
British Psychological Society	Guideline	Rec 5.4	Comprehensive assessment is, of course, fundamental to effective multidisciplinary rehabilitation. 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. 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.
Scottish Intercollegiate Guidelines Network (SIGN) Council	Guideline	Rec 5.4	Add to start of recommendation, "Where multidisciplinary rehabilitation is available, assess....."
Clinical Advisors to the Scottish Government (Clinical Guidance Cell, Professional Advisory Group)	Guideline	Rec 5.4	Not clear what this means. Presumably the person seeing the patient has done the referral and the referral pathway exclusion and inclusion criteria will have been met to ensure suitability and safety? What would be more useful is information on who would benefit from rehab and who to refer. By referring to an integrated MDT.
Long Covid Support Group	Guideline	Rec 5.4	Emphasise that assessment and treatment of organ or inflammatory damage should happen before rehabilitation. Emerging research is showing that organ damage is not uncommon after several months in people with Long Covid, including those who were not hospitalised. Standard diagnostic tests were not able to detect this damage, which was uncovered by novel diagnostic tools. Examples of such research: Gleeson et al, Oxford, lung damage using Xenon scans Puntmann et al, Frankfurt, cardiac damage using MRI Perspectum, Banerjee et al, Oxford, cardiac, lung, liver damage using MRI What

Stakeholder	Document	Section	Comments
			are the proposals for identifying and investigating 'any symptoms that could affect the person's safety to start rehabilitation'?
Royal College of Speech and Language Therapists (RCSLT)	Guideline	Rec 5.4	Multidisciplinary rehabilitation is critical to rehabilitation and/recovery of people after COVID. People must be able to access the right rehabilitation when and where they need it. Failure to provide access to rehabilitation will result in a deterioration in people's physical and mental health needs.
Engender	Guideline	Rec 5.5	This must consider gendered barriers in terms of women's lives as already referred to as well as gender bias in treatment and diagnostics. Women should not be dismissed or see pain minimised. Where there are likely to be multi-system symptoms and multiple medical experts involved, sex and gender differences must be acknowledged at every possible stage.
Royal College of Occupational Therapists	Guideline	Rec 5.5	line 5: "helping the person to decide and work towards occupation-focused goals"
Forth Valley Patient Public Partnership	Guideline	Rec 5.5	Again ownership vital
Faculty of Health Sciences, Oxford Brookes University	Guideline	Rec 5.5	It is also completely unclear who this is directed at. Very few readers will know what a rehabilitation prescription is, and this needs to be enlarged upon if it is to remain. The whole structure of this recommendation is wrong, and needs to be written in a way that is clear to the reader.
Cardiff and Vale UHB	Guideline	Rec 5.5	in a rehabilitation prescription the concept of a rehabilitation prescription is really an NHS England onyt terminology, and largely related to major trauma rehabilitation, suggest it is not used in this guidance as it does not fit well with AHP professional autonomy and devalues the personalised rehabilitation approach based on individual assessment and co-produced treatment plan with the patient.
Patient Advisory Group to the	Guideline	Rec 5.5	Patients who meet the diagnostic criteria for ME/CFS, and who do not have additional symptoms that are not part of the symptoms of ME/CFS, should be advised to pace themselves, keeping their activity

Stakeholder	Document	Section	Comments
CFS/ME Research Collaborative (CMRC)			levels within their energy envelope (see draft ME/CFS guidelines). Based on the experiences of ME/CFS patients, goals outside of a patient's energy envelope may be detrimental.
Chartered Society of Physiotherapy	Guideline	Rec 5.5	5.5: We feel this needs further development by experts in currently delivering COVID rehabilitation. There is mention of planning, but no description of the mode or mechanism of delivery of rehabilitation / interventions. Also, the rehabilitation prescription needs to be defined.
Royal College of General Practice England, Wales, Scotland and Ireland	Guideline	Rec 5.5	The term brain fog is not a medical term/diagnosis. Can the committee consider using "cognitive problems (brain fog)" as on page 20 for consistency? Can the committee state that a rehabilitation plan is to be made by the rehabilitation team? This is a specialist service. Can the committee consider changing to 'managing' fatigue Currently states treating' fatigue.
Long Covid Wales	Guideline	Rec 5.5	The multidisciplinary subsection of section 5 would need an initial explanatory note that most patients will require a period of convalescence before rehabilitation is appropriate. Regarding 5.5, considering the large number of patients who have been self-managing for months with SpO2 well below 94% it would be relevant to highlight the need for adequate monitoring of saturations – perhaps by home monitoring as it may not always be picked up during a limited exercise test in clinic – prior to providing symptom management for breathlessness.
British Society of Rehabilitation Medicine (BSRM)	Guideline	Rec 5.5	We absolutely support the use of the Rehabilitation Prescription. However this concept may be new to professionals managing these patients. Direction should be given to resources which describe the RP, how to develop it, when to do so etc. The BSRM website has those resources. Teams new to the RP could liaise with Major Trauma Centres, to see how the RP can be developed for their locality The rehabilitation management plan must involve family/carers for those who are unable to self direct their rehabilitation for either cognitive or psychological reasons
Action for M.E.	Guideline	Rec 5.5	Remove rehabilitation and put in stabilisation. Not everyone will be moving towards a plan with increased activity. It is important for people to stop and listen to their body and understand that going beyond what they are able to can have a worsening impact on the condition.
Long Covid SOS	Guideline	Rec 5.5	must exercise caution with any form of goal setting - graded exercise programmes could set people with LC back severely. Goal setting even by patients themselves could be very risky - pacing might be

Stakeholder	Document	Section	Comments
			more appropriate Consider asking patients to monitor their heart rates to ensure they don't enter the 'danger zone'' which can trigger relapses for some
ME Action UK	Guideline	Rec 5.5	“advice and education on managing... fatigue”. This should include post-exertional symptom exacerbation(PESE), and then refer to the draft ME/CFS guideline by NICE. This will give clinicians significantly more detailed and clearer advice on how this symptom can be mitigated through energy management (commonly called pacing). The aim is to avoid flares and relapses by remaining within the person’s ‘energy envelope’. If clinicians seeing post-COVID-19 patients do not take into account the high proportion of people with fatigue and give appropriate advice on energy management, this could harm a substantial subset of long COVID patients. There is no reference throughout the whole document to convalescence, recuperation or rest. We see a focus on “helping the person to decide and work towards goals”, without evidence of efficacy, which implies there is a known pathway to a smooth recovery. We would like to see the addition of rest to this section - for example, an additional bullet point that says “advice on the role of rest”.
National Guideline Centre	Guideline	Rec 5.5	Recommendation 5.5 (and the accompanying rationale on page 19) is somewhat circular, noting that, ‘There was very little evidence on interventions, but the panel agreed that everyone should have self-management support and information’. The recommendation of unspecified ‘interventions’, without reference to potential harms, is concerning. For people who have symptoms consistent with ME/CFS, the recommendations 1.11.4 – 1.11.6 and 1.11.20 in the draft ME/CFS guideline should be considered. Any programme of rehabilitation should be delivered or overseen by a physiotherapist or occupational therapist with appropriate training and expertise.
West Yorkshire and Harrogate Health and Care Partnership	Guideline	Rec 5.5	This section requires more detail to guide multidisciplinary rehab services, team development etc. there could be incorporation of relevant parts of guidelines on rehab for other issues e.g. stroke, chronic fatigue.
British Psychological Society	Guideline	Rec 5.5	We agree that developing a personalised rehabilitation and management plan is crucial. 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. 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”

Stakeholder	Document	Section	Comments
			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.
Clinical Advisors to the Scottish Government (Clinical Guidance Cell, Professional Advisory Group)	Guideline	Rec 5.5	What is the specific advice on symptom management? This could be elaborated on or linked. Absolutely. Given breath of symptoms it will need to be tailored.
Long Covid Support Group	Guideline	Rec 5.5	Line 5: Using language such as ‘goals’ risks people pushing themselves (potentially triggering worsening of symptoms) and also feeling a failure if goals are not achieved.
Royal College of Speech and Language Therapists (RCSLT)	Guideline	Rec 5.5	Survivors report fluctuating and changing difficulties over weeks/month. This must be built into planning decisions and the personalised rehabilitation plan must be regularly reviewed and updated as people’s needs change. This needs to include referral to specialist clinics for some specific specialist interventions e.g. joint ENT and speech and language therapy voice clinics for ongoing dysphonia
Forth Valley Patient Public Partnership	Guideline	Rec 5.6	Again provided these are robust and systems age friendly
Faculty of Health Sciences, Oxford Brookes University	Guideline	Rec 5.6	Unless there is a specific tracking app available, this is unclear as it is not certain what you mean by a tracking app. Simply recording steps taken per day or distance walked per day is not going to be useful to the great majority of people. There is a lack of practical realism in this.

Stakeholder	Document	Section	Comments
Cardiff and Vale UHB	Guideline	Rec 5.6	. As well as tracking apps should be used for supporting rehabilitation. An NHS Wales COVID rehab app is under development and should be published pre Christmas
The Poverty Alliance	Guideline	Rec 5.6	Tracking apps will only work for people with appropriate technology and digital engagement skills as well as data access, options should be provided for alternatives to capture experiences.
Chartered Society of Physiotherapy	Guideline	Rec 5.6	5.6: Add 'and that these should be used collaboratively with HCP's to evaluate and monitor outcomes'
Long Covid Wales	Guideline	Rec 5.6	It would be appropriate to again highlight the phenomenon of post-exertional malaise as setting goals may lead to patients overexerting themselves leading to a setback or relapse an undefined time later.
British Geriatric Society	Guideline	Rec 5.6	Is there a link to a direct.gov website which GPs could use to print off and send to patients who do not have internet access?
Action for M.E.	Guideline	Rec 5.6	Add deterioration. Not every patient will experience a recovery at any one time and expectations need to be set. Tracking a deterioration of symptoms can identify whether some activity of management techniques are having a harmful affect on health.
Long Covid SOS	Guideline	Rec 5.6	Every person has a different way of coping with illness. Whilst this may help for some, it could be unhelpful for others. Some do not want to constantly be reminded on how incapacitated they are and rather focus on what they can do. This is a wellbeing issue and should not be overly prescriptive. Are there any ways to flag things which should be noted if they happen once a holistic understanding of the patient is known?
ME Action UK	Guideline	Rec 5.6	At present, there is not enough evidence to know what the prognosis is for people with long COVID, yet the focus on goals and recovery assumes that the person's health will improve. Evidence from ME/CFS, which has post-exertional symptom exacerbation as the hallmark feature, has been excluded from the scope. However, this demonstrates that only a minority of those with ME/CFS recover. It would be wrong to extrapolate this to all people with long COVID, but assuming most will recover is also unfounded. We suggest changing this recommendation to: "Encourage people to keep a record of, or use a tracking app to monitor, their activities and any changes in their symptoms (also see the section on follow-up and monitoring).
West Yorkshire and Harrogate	Guideline	Rec 5.6	Guidance on what app should be used would be useful. This may lead to barriers for people who are digitally excluded.

Stakeholder	Document	Section	Comments
Health and Care Partnership			
British Psychological Society	Guideline	Rec 5.6	We agree with this recommendation with respect to goal monitoring which is central to effective rehabilitation. 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)
Clinical Advisors to the Scottish Government (Clinical Guidance Cell, Professional Advisory Group)	Guideline	Rec 5.6	What should they record? What App should be used and has been validated? Needs to be more specific. What governance of the app. Who will it 'link it' will it link to an electronic record. That app cannot simply be in isolation for use by the person themselves. It needs to be a value added step and not potentially lead to anxiety either because it is not used or is used. Could potentially be a powerful research tool for data but how data is used would need to be explicit to user.
Long Covid Support Group	Guideline	Rec 5.6	Line 9: Using language such as 'goals' risks people pushing themselves (potentially triggering worsening of symptoms) and also feeling a failure if goals are not achieved.
BAME Health Collaborative (BHC)	Guideline	Rec 5.6	5.6. Encourage people to keep record of, or use a tracking app to monitor their goals, recovery and any changes in their symptoms, employing methods and means that are reflective of the diverse levels of education, backgrounds, beliefs of the population of the UK.
Engender	Guideline	Rec 5.7	There are likely to be further groups needing additional support, which should be developed with specific expertise. However this should not result in siloed care or expertise.
Forth Valley Patient Public Partnership	Guideline	Rec 5.7	As above Special requirements for the elderly and possible involvement of charities like Help the Aged
Carers Scotland	Guideline	Rec 5.7	Add "their carers" after "older people" on line 12

Stakeholder	Document	Section	Comments
Chartered Society of Physiotherapy	Guideline	Rec 5.7	5.7: This is too restrictive. This should be for anyone who needs it irrespective of age.
Royal College of General Practice England, Wales, Scotland and Ireland	Guideline	Rec 5.7	Support should not only be for older adults and children. People of any age may need support packages if they are isolated and severely affected so this should not just include older people. Please consider renaming this subheading “specialist considerations”
Patient-Led Research for COVID-19	Guideline	Rec 5.7	We recommend considering changing this title to “Additional supports.” On line 12, we recommend removing “older” or adding additional populations because additional supports listed here are needs of all ages of Long COVID patients.
British Geriatric Society	Guideline	Rec 5.7	More guidance would be welcome in the "older people" section. Is there any evidence about the natural history and prognosis of ongoing covid in older people, or its prevalence? I have highlighted concerns that older patients without a positive covid swab and atypical symptoms may be missed in the community. The atypical presentation of covid is not unlike that of other viruses causing non-specific symptoms in older people, which may be similar to previous episodes caused by other illnesses and therefore atypical symptoms are unlikely to raise the suspicion of acute covid in patients, carers or clinicians. Expecting older people in the community to perform their own covid swab is often not practical or possible. If they decline advice to get swabbed or have not fulfilled the 111 testing criteria, swabs will not be done acutely unless they need admission to hospital. It is not clear whether the covid MDT assessments will be taking place in people's homes or whether patients would be expected to get to a building? How would mobility, sensory and cognitive impairments be accounted for? Would the MDT discuss advance care planning with the patient and family as part of the holistic approach?
Public Health Scotland	Guideline	Rec 5.7	An explanation of how to achieve these would be useful.
British Society for Immunology	Guideline	Rec 5.7	We would advise that additional support should be extended not only to older people and children, but also to people with co-morbidities that exacerbate risk of long-COVID syndrome. This is a theme that could be introduced throughout this document.

Stakeholder	Document	Section	Comments
West Yorkshire and Harrogate Health and Care Partnership	Guideline	Rec 5.7	We need to also include further support and adjustments for people with disabilities, e.g. people who are blind, deaf, and people with hidden disabilities e.g. autism.
British Psychological Society	Guideline	Rec 5.7	Agree
Clinical Advisors to the Scottish Government (Clinical Guidance Cell, Professional Advisory Group)	Guideline	Rec 5.7	Older people and all those with other specific needs. If dementia older people and carers.
Long Covid Support Group	Guideline	Rec 5.7	People of any age who live alone may require care packages and support with isolation and loneliness.
Deaf Scotland	Guideline	Rec 5.7	Hearing/Vision assessments done?
Forth Valley Patient Public Partnership	Guideline	Rec 5.8	Particular needs of children Involvement ofthird sector.
Faculty of Health Sciences, Oxford Brookes University	Guideline	Rec 5.8	Another example of the inconsistency within this guideline, referring to matters at four weeks after onset.

Stakeholder	Document	Section	Comments
The Royal College of Obstetricians & Gynaecologists	Guideline	Rec 5.8	Lines 16-18. Text says 'Consider early referral between 4 and 12 weeks for specialist advice for children with ….. post-COVID-9 syndrome'. From the definitions given on page 2, these individuals can't have a diagnosis of post-COVID-19 syndrome yet.
Patient-Led Research for COVID-19	Guideline	Rec 5.8	On line 17 consider removing "for children" -- all Long COVID patients should be offered early referral for specialist advice regardless of age. We recommend talking with parents of children with Long COVID for specific additional support that population needs.
Public Health Scotland	Guideline	Rec 5.8	Are paediatrics developing a specialist service for this?
National Guideline Centre	Guideline	Rec 5.8	Recommendations 5.7 and 5.8 puts older people and children under the same heading yet that seems to be little evidence of post-COVID-19 syndrome in children. It would therefore be very important to emphasise that referral for children would be for specialist advice on excluding other conditions and that would be from a general paediatrician. Unless the nature of this specialist advice is clarified, this part of the guideline reads as in conflict with the guidance in the ME/CFS guideline. The guideline should be clear that 'post-COVID-19 syndrome' in children and young people is not the same as the 'Paediatric Inflammatory Multisystem Syndrome – Temporally associated with SARS-CoV-2 pandemic (PIMS-TS)' which requires specialist care, investigation and treatment.
The Richmond Group of Charities	Guideline	Rec 5.8	When considering support for children, the guidance should also include consideration of their mental health and wellbeing needs including support for loneliness and social isolation.
British Psychological Society	Guideline	Rec 5.8	Agree
Lifestyle, Exercise and Nutrition Improvement (LENI)	Guideline	Rec 6.1	Please allow us a general comment for Section 6: Any recommendations on the management and follow-up plans are purely dependent on local availability of support services. Therefore, the primary aim would be for these to exist, otherwise, any advice (without further support) will be obsolete. For 6.1 specifically, we would recommend that any plan should be recommended by the healthcare professional and agreed with the person suffering, rather than simply agreed - the healthcare professional should really lead the process.

Stakeholder	Document	Section	Comments
Research Group			
Cardiff and Vale UHB	Guideline	Rec 6.1	We are really keen to ensure that Long COID is not over medicalised. We do not support the setting up of secondary care specialist clinics, but rather favour that this is primary care driven, supported by a rehab MDT, with access to expert secondary care advice as and when needed, rather than making this a secondary care specialism. AS recovery is likely to be protracted for many it is important to manage expectations , and not seek a “cure” by over investigating and creating dependency. Rehabilitation guided by AHPs , with support from a wider MDT only when needed is key.
The Poverty Alliance	Guideline	Rec 6.1	This needs to take into account barriers people may face such as travel within rural areas or the cost of accessing transport.
Chartered Society of Physiotherapy	Guideline	Rec 6.1	6.1 In general for section 6: Who should be doing this, are these recommendations for those that are not entering into clinics but are self-managing independently? Is the audience for this section GP’s?
ICUsteps Peer Support Charity	Guideline	Rec 6.1	25% of ICUs have a formal follow up service for recovering ICU patients, including post Covid. Professionals in contact with the patient should be aware of local ICU follow up services to ensure that they do not slip through the net.
British Society of Rehabilitation Medicine (BSRM)	Guideline	Rec 6.1	As before, for those unable to self direct or self manage, the involvement of family/carers is essential
British Psychological Society	Guideline	Rec 6.1	Agree
Clinical Advisors to the Scottish Government (Clinical Guidance Cell, Professional	Guideline	Rec 6.1	Monitoring, is this supported monitoring or self-reported interaction? Greenhaulgh A recommends more research to define interpretation and follow up requirements. Telemonitoring using a sats probe cited …but again requires further research for the context.

Stakeholder	Document	Section	Comments
Advisory Group)			
Long Covid Support Group	Guideline	Rec 6.1	Take into account the relapsing-remitting nature of the condition and that serious pathologies can emerge weeks or months post infection with SARS-CoV-2. Provide recognition and reassurance that symptoms may fluctuate, and that patients should not be wary of seeking medical advice if they need to.
Carers Scotland	Guideline	Rec 6.2	The guideline should note the need to explain that support can be made available to assist the person with their appointment. For example, a carer can support the individual with a digital appointment.
National Guideline Centre	Guideline	Rec 6.2	The emphasis in recommendation 6.2 on shared decision making is welcome.
British Psychological Society	Guideline	Rec 6.2	Agree
MSD Ltd	Guideline	Rec 6.2	MSD suggests that the decision-making process for face-to-face consultations should aim to facilitate presence of a trusted relative/friend/carer with the person if feasible. Consider that this could be a key aspect in helping person to feel adequately supported through management of ongoing symptomatic COVID-19 or post-COVID-19 syndrome.
Clinical Advisors to the Scottish Government (Clinical Guidance Cell, Professional Advisory Group)	Guideline	Rec 6.2	Absolutely. Realistic Medicine. However choice that is along the principle of beneficence and benefit to all and adds value to the individual and the whole system.
Royal College of Speech and Language	Guideline	Rec 6.2	We believe it is critical to get the balance right here. Balancing the wishes of clinicians versus the person’s preferences, which may not be the same, and understanding how this conflict can be addressed.

Stakeholder	Document	Section	Comments
Therapists (RCSLT)			
Engender	Guideline	Rec 6.3	We would reiterate that there is a need here to consider flexible access to care which ensure clinics are not constricted by barriers such as appointments times that conflict with school pick up and drop off and the previous comments about gender bias in diagnostics. There are some reports that long-covid has disrupted women's menstrual health, but generally there is a need to ensure multi-disciplinary teams take into account women's health, including maternity, contraception and fertility depending on personal circumstances.
Lifestyle, Exercise and Nutrition Improvement (LENI) Research Group	Guideline	Rec 6.3	This section implies regular check-ups, however, these are not noted anywhere in the guidelines. We recommend that these are defined at earlier stages of the guidelines.
Faculty of Health Sciences, Oxford Brookes University	Guideline	Rec 6.3	As a recommendation, I would be worried that it risks doing harm by maintaining a focus upon symptoms. It would seem better to recommend recording improvements in activities over time or, if preferred, levels of activity being achieved. Asking people to record symptoms risks maintaining symptoms and disability.
Chartered Society of Physiotherapy	Guideline	Rec 6.3	6.3: Consider adding monitoring of mental health and wellbeing to this section also.
British Psychological Society	Guideline	Rec 6.3	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.
Clinical Advisors to the Scottish Government	Guideline	Rec 6.3	May be a challenge given the range of symptoms possible presenting. But certainly for more severe symptoms that require intervention it may be easier. Kamal cites low critical ad high critical range of symptoms. Potential to consider as evidence base expands.

Stakeholder	**Document**	**Section**	**Comments**
(Clinical Guidance Cell, Professional Advisory Group)			
Faculty of Health Sciences, Oxford Brookes University	Guideline	Rec 6.4	This also risks prolonging illness and invalidity, and it risks increasing anxiety. Is there any evidence to support this? Has the risk of harm, both psychological and practical been considered?
Patient Advisory Group to the CFS/ME Research Collaborative (CMRC)	Guideline	Rec 6.4	Suggest inclusion of a symptom diary as a possible means of self-management, particularly with regards to monitoring energy levels and exercise capacity and recognising triggers for post-exertional malaise, which may be delayed by up to 72 hours after the triggering activity.
British Geriatric Society	Guideline	Rec 6.4	It would be useful if there is also guidance as to who the patient reports back to with their self monitored information- will it be to the hub MDT or to the GP, and what will the possible thresholds be to determine what happens next? Is this a one off assessment or ongoing monitoring? From personal experience of advising patients to do their own self monitoring, very clear instructions are needed to avoid unnecessary anxiety on the part of the patient, carer, and clinician, with clear goals as to frequency of monitoring and when to report urgently or out of normal working hours.
Oxford University Hospitals NHS FT	Guideline	Rec 6.4	home monitoring may be helpful but may also increase anxious focus on illness.
Patient Safety Learning	Guideline	Rec 6.4	Need to ensure that there is a recommendation for the provision of home/community support so that people living with Long COVID can access these services from primary and/or community health services.

Stakeholder	Document	Section	Comments
National Guideline Centre	Guideline	Rec 6.4	In recommendation 6.4 it would be helpful to set parameters for the person to call for support over fluctuations in heart rate, blood pressure and pulse oximetry. The current wording is too vague to be particularly helpful to patients or general practitioners.
British Thoracic Society	Guideline	Rec 6.4	The self-monitoring of oxygen saturation is vague and needs clarification.
West Yorkshire and Harrogate Health and Care Partnership	Guideline	Rec 6.4	Clarity would be helpful on oximetry – who should self monitor at home, how should this be resourced.
British Psychological Society	Guideline	Rec 6.4	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.”
Clinical Advisors to the Scottish Government (Clinical Guidance Cell, Professional	Guideline	Rec 6.4	What is the availability of this? If it is a clear recommendation who will vulnerable groups access this? Yes but again may not be suitable for all and may widen digital exclusion. Would it be supported or unsupported monitoring?

Stakeholder	Document	Section	Comments
Advisory Group)			
Long Covid Support Group	Guideline	Rec 6.4	Self-monitoring at home should also be considered in the earlier weeks post infection, and not reserved for 12+ weeks after infection.
Engender	Guideline	Rec 6.5	There is also a need to proactively monitor trends and emerging data disaggregated by sex when assessing bringing in expertise to multi-disciplinary teams which may suggest particular groups are more likely to require aspects of care than others so as to ensure speedy access to experts.
Cardiff and Vale UHB	Guideline	Rec 6.5	Red Flags It would be extremely helpful to have a list of the red flags for the main presenting subspecialty areas of respiratory, cardiology and neurology. This would reduce unnecessary referral to secondary care services , aiming to de medicalise Long COVID, without a list of red flags it is likely that people with ongoing symptoms, will push for a secondary care referral, when for the majority this is not necessary. It would also assure primary care clinicians that they are capable of managing very appropriately the majority of Long COVID patients.
Long Covid Wales	Guideline	Rec 6.5	Some symptoms can and do present weeks or months after the onset of Long COVID. Of concern are, for example, neurological conditions such as demyelination, which has affected one of the co-authors of a letter to the BMJ (https://www.bmj.com/content/370/bmj.m3565.short), but, of course, there will be others. Please see comments to section 2.2 for further examples.
British Geriatric Society	Guideline	Rec 6.5	Please include more information about what is known about potential conditions/ symptoms needing referral or investigation (or a link to your covid recovery if this is what is meant).
British Psychological Society	Guideline	Rec 6.5	Agree – this could include physical or psychological symptoms.
Mast Cell Action	Guideline	Rec 6.5	keeping a record of how a patients symptoms evolve and change over time is incredibly important. Ask the patient to keep a structured diary. (there are various tempates available on line) In respect of gastrointestinal and allergy symptoms that develop or get markedly worse specialiast in these areas may need to be involved in care?
Clinical Advisors to the Scottish Government	Guideline	Rec 6.5	yes

Stakeholder	Document	Section	Comments
(Clinical Guidance Cell, Professional Advisory Group)			
Neurological Alliance	Guideline	Rec 6.5	Strongly suggest that 'red flag' symptoms are explicitly included in the document. 'Red flag' symptoms are reference in 4.1, but not expanded upon.
Royal College of Speech and Language Therapists (RCSLT)	Guideline	Rec 6.5	We suggest that the guideline does not assume that new symptoms are related to long covid, to avoid the potential to overlook a different unrelated medical problem
National Voices	Guideline	Rec 6.5	We are supportive of the emphasis on shared decision making about the most appropriate ways to organise care (remote or face to face etc). Our I Statements set out the reasonable expectations people have of how they should be treated; people with health conditions remain aware that healthcare will be different from usual, yet they expect to continue to be communicated with and treated with respect, and our report sets out practical suggestions. We would recommend that the I Statements in particular be used as a standard to analyse the guidelines against. https://www.nationalvoices.org.uk/what%20we%20need%20now
Lifestyle, Exercise and Nutrition Improvement (LENI) Research Group	Guideline	Rec 7.1	Sharing information requires appropriate consent by the patient. As this is not automatically exist, it should be checked at the earliest possible opportunity.
Faculty of Health Sciences, Oxford	Guideline	Rec 7.1	Another badly written recommendation. Share with whom?

Stakeholder	Document	Section	Comments
Brookes University			
Polymyalgia Rheumatica and Giant Cell Arteritis Scotland (PMR-GCA Scotland)	Guideline	Rec 7.1	"Promptly" is of the essence if this information is to affect self or professional management.
Carers Scotland	Guideline	Rec 7.1	The important role of carers is completely missing here. Family carers are often the main support for an individual and, with the person's consent (or where a person lacks capacity), relevant information should be shared with them to support them to provide care to the individual and to support their rehabilitation. They are an important part of, for example, self management and as such sharing of information is important.
Chartered Society of Physiotherapy	Guideline	Rec 7.1	7.1: Should include copies of all relevant documentation including referral, assessments and screening materials.
British Society of Rehabilitation Medicine (BSRM)	Guideline	Rec 7.1	The concept is absolutely supported. Shared electronic records between primary, secondary & tertiary care would be ideal, but we recognise that this technology is not available everywhere. Where there are opportunities to share clinical information digitally/electronically, this should be encouraged.
British Geriatric Society	Guideline	Rec 7.1	Care plans- is there an example to share and are these created by the covid MDT or will they be expected from GPs?
Patient Safety Learning	Guideline	Rec 7.1	We believe this should be expanded to clarify who is being asked to share information and with whom. For example, the Long COVID clinic, primary care, and community services as well as people living with Long COVID?
CDH UK - The Congenital	Guideline	Rec 7.1	Consider providing information on who to contact in cases of lost records, paperwork and how to make a complaint about care or raise concerns. Make reference to ensuring that the patient understands

Stakeholder	Document	Section	Comments
Diaphragmatic Hernia Charity			their follow up/continuity of care plan as they can become confused if information is not clear and well signposted.
British Psychological Society	Guideline	Rec 7.1	Agree
Clinical Advisors to the Scottish Government (Clinical Guidance Cell, Professional Advisory Group)	Guideline	Rec 7.1	This needs to be elaborated on or reworded. Patient records are not routinely available.
Long Covid Support Group	Guideline	Rec 7.1	Sharing of information/continuity of care is something that is already failing to happen in the NHS, with patients having to act as administrators/coordinators of their own care. ‘Care plans’ in existing services are not updated/shared/adhered to. While this a welcome proposal, what infrastructure changes need to happen to facilitate this?
Deaf Scotland	Guideline	Rec 7.1	Section 7 Is the process accessible? Will parts of extended teams be accessible, deaf/equality aware?
National Voices	Guideline	Rec 7.1	Please see our report on virtual care over the pandemic: https://www.nationalvoices.org.uk/publications/our-publications/dr-will-zoom-you-now-getting-most-out-virtual-health-and-care
Faculty of Health Sciences, Oxford Brookes University	Guideline	Rec 7.2	Another badly written recommendation. What baseline measures? When is the baseline? One day after onset? Before the illness? At four weeks? I would fully support having a patient held document that records everything from the outset, but given the parlous state of NHS information technology, this is not achievable. This recommendation needs to be more specific, and probably fairly restrained in what it recommends.
Chartered Society of Physiotherapy	Guideline	Rec 7.2	7.2: This should include ongoing outcome assessments not just baseline.

Stakeholder	Document	Section	Comments
British Society of Rehabilitation Medicine (BSRM)	Guideline	Rec 7.2	This should also include a record of functional abilities using a validated measure, which should include aspects of cognition which may impact on informed decision making in relation to care & treatment.
British Geriatric Society	Guideline	Rec 7.2	This would be very useful but discharge letters rarely give oxygen and heart rates at discharge, usually on admission, if at all. Can this be flagged with secondary care to become standard practice? It is not clear whether this guidance is aimed at secondary care as well as primary care.
British Psychological Society	Guideline	Rec 7.2	Agree
Clinical Advisors to the Scottish Government (Clinical Guidance Cell, Professional Advisory Group)	Guideline	Rec 7.2	What tools are being referred to? Need to elaborate. Yes. This Is essential good practice now out with Covid 19.
Forth Valley Patient Public Partnership	Guideline	Rec 7.3	Compatibility of systems Economic considerations for use ofI T bypatients
Lifestyle, Exercise and Nutrition Improvement (LENI) Research Group	Guideline	Rec 7.3	We don't feel that the process described in 7.3 is feasible on a large scale for NHS under the current circumstances (e.g., available technology, personnel availability).. Please refer to relevant literature.

Stakeholder	Document	Section	Comments
Faculty of Health Sciences, Oxford Brookes University	Guideline	Rec 7.3	An unhelpful recommendation. Who should do the thinking? Where is it supposed to lead? Are you trying to encourage healthcare systems to have a much better method for integrating services? Are you talking about teams discussing their work in general? Or is this relating to information about an individual patient?
British Society of Rehabilitation Medicine (BSRM)	Guideline	Rec 7.3	Isn't this a "must"? That way you should also be able to involve patients if required
British Geriatric Society	Guideline	Rec 7.3	How will Primary Care Networks and secondary care specialists integrate with covid hubs? Will the covid MDT be responsible for seeking specialist advice directly from the hospital?
Patient Safety Learning	Guideline	Rec 7.3	We believe this should be strengthened. Multidisciplinary team meetings should not just be thinking about ways to do this but ensuring that improvements happen.
British Psychological Society	Guideline	Rec 7.3	Agree
Clinical Advisors to the Scottish Government (Clinical Guidance Cell, Professional Advisory Group)	Guideline	Rec 7.3	Who "thinks" about this? This is about system changes and operational change so a national guideline needs to define what change is required and if so who is responsible for implementing it. What is the composition of the MDT referred to? Who has responsibility for this? Yes. Recommend a curated and maintained repository. Easily signposted to.
National Voices	Guideline	Rec 7.3	The focus on multi disciplinary teams is welcome. It would be welcome to include link workers/ social prescribers/ peer support workers or care coordinators in the definition of these teams, as well as advocates or carers where these are involved.

Stakeholder	Document	Section	Comments
Engender	Guideline	Rec 7.4	We reiterate the need for multi-disciplinary care to include aspects of women's health and to guard against minimising women's pain, symptoms or creating a path dependency due to gendered biases assumption such as anxiety, stress or not believing women
Faculty of Health Sciences, Oxford Brookes University	Guideline	Rec 7.4	But this does not address the issue that people may well be seen in multiple services, given the poorly coordinated and designed patchwork of services that exist. If someone is being seen in mental health services for their anxiety induced by monitoring their oxygen level, and in a pulmonary rehabilitation service for their pulmonary problems, and possibly another service for difficulties with walking, who is going to be the single point of contact?
Chartered Society of Physiotherapy	Guideline	Rec 7.4	7.4: Is this not part of section 8?
Patient Safety Learning	Guideline	Rec 7.4	This is an excellent ambition. Should this be commissioned/delivered by the Long COVID clinics or will it be the responsibility of the GP? Is this an additional service? Where will be funding for this come from?
Long Covid SOS	Guideline	Rec 7.4	This is a very important and having a care coordinator would be extremely helpful. As patients the various pathways and interfaces within the NHS can be draining, inaccuracies creep in because of late write ups and you can get referrals you can't follow up. This can be very stressful and the administrative management burden should be eased for the patient.
Royal College of Nursing	Guideline	Rec 7.4	As stated in earlier comments, nursing workforce need funding to support effective implementation
British Psychological Society	Guideline	Rec 7.4	Agree
Clinical Advisors to the Scottish Government (Clinical Guidance Cell, Professional	Guideline	Rec 7.4	Based where? Primary care? Psychiatry? If symptoms merit.

Stakeholder	Document	Section	Comments
Advisory Group)			
Long Covid Support Group	Guideline	Rec 7.4	Again the proposal that patients should have a care coordinator/single point of contact is to be applauded. People with Long Covid are now months into a diagnostic odyssey and feel like they are passed from pillar to post with no sense that anyone is taking ownership of their condition. Even in the newly established Post-covid clinics, we are hearing unsettling accounts of unsatisfactory experiences where patients feel unheard and are no closer to having their symptoms managed. One of our group members reported this experience from 30 Nov 2020: “Hi all, just left the hospital in tears and extremely disheartened. The Long Covid 'clinic' is basically an extension of A&E. A nurse did standard blood pressure, bloods, ECG tests. Results clear as expected. 5 mins chat with a doctor who told me to tell my GP to refer me to Neurology. He's put me on the waiting list for the breath test (warned its a long list) and waiting list for heart echo. So that's it. He wasn't really interested in the diarrhoea (advised to take a sample to the GP) internal tremors or other random symptoms. Kept asking about if there's family history of X or Y. I just broke down, I told them no, I was a normal, healthy woman before Covid. The nurse could only offer sympathy. In my mind they are still, even at this clinic, not looking at Long Covid symptoms as a whole. Separate clinics for various symptoms will not help them understand what Long Covid does to those unfortunate enough to suffer.” What are the recommendations for facilitating effective services in terms of staffing structure/funding, etc.?
Engender	Guideline	Rec 8.1	Need to consider placement of clinics and travel, timing etc. We reiterate the need for multi-disciplinary care to include aspects of women's health and to guard against minimising women's pain, symptoms or creating a path dependency due to gendered biases assumption such as anxiety, stress or not believing women. Sex difference in for example cardiology must not be discounted in referral pathways, diagnostics or rehabilitation plans.
Royal College of Occupational Therapists	Guideline	Rec 8.1	Page 12, line 5: The recognition of the importance of multidisciplinary clinics and rehabilitation services is very welcome, however the reality of services providing these without the provision of additional resources is extremely challenging. Rehabilitation services are already stretched and under-resourced, and there is a significant risk of ‘robbing Peter to pay Paul’ if staff are taken away from their normal duties in order to exclusively support individuals recovering from Covid. Thought needs to be given on how to balance the rehab needs of ‘post-Covid’ patients with the rehab needs of the wider population. In some cases this is likely to be realised by incorporating post-Covid patients into existing community rehabilitation services, rather than separate Covid services. In all models of service organisation, making adequate, additional resources available will be essential. RCOT recommends adopting a

Stakeholder	Document	Section	Comments
			tiered 'pyramid' approach to service organisation and rehab provision, in order to best utilise workforce and meet demand: Universal – those in the highest numbers but with the most straightforward needs. These people will be able to self-manage with minimal support or follow-up from primary care, for example using www.yourcovidrecovery.nhs.uk Targeted – middle tier of people whose needs are still relatively straightforward but who will need light-touch support from a health professional(s), likely to be primary care or a community clinic, to self-manage their recovery e.g. using www.yourcovidrecovery.nhs.uk Specialist –people with most complex health and support needs. This tier will require personalised input from rehabilitation MDT.
Forth Valley Patient Public Partnership	Guideline	Rec 8.1	Definitely the way forward in dealing with this long term complex condition
Lifestyle, Exercise and Nutrition Improvement (LENI) Research Group	Guideline	Rec 8.1	There needs to be a brave recommendation/guideline of establishing long COVID-19 clinics in as many areas as possible, rather than the advice to "consider the establishment". The rationale behind the proposed guidelines, clearly supports this.
Faculty of Health Sciences, Oxford Brookes University	Guideline	Rec 8.1	This should specify that the medical doctor is a consultant in rehabilitation, as this will be the only person who is going to have the breadth of knowledge and skill to cover all aspects of the problems posed in patients after Covid 19.
Cardiff and Vale UHB	Guideline	Rec 8.1	not in secondary care. the service needs to be primary care led. do not need to have all specialties together to manage this cohort. the treatment is largely AHP led rehabilitation. agree the pathway across the systems and use skills appropriately. a "specialist clinic" will over medicalise and create dependency
Polymyalgia Rheumatica and Giant Cell	Guideline	Rec 8.1	If these can be provided and made accessible for the majority of patients they would make a real difference, allowing expertise and best practice to be available to all. I would expect patients to be willing to travel a greater distance if they thought that a single appointment, even a prolonged one,

Stakeholder	Document	Section	Comments
Arteritis Scotland (PMR-GCA Scotland)			could mean many services were available. Continuity of care with a provider who knows the patient and is known to them is not only desirable but also more efficient in long-term and chronic conditions.
UK Doctors Long COVID Group	Guideline	Rec 8.1	Why does 8.1 state ‘consider providing’ and 8.2 state ‘provide’? One stop multidisciplinary clinics for assessment of physical and mental health symptoms (8.1) are just as important as the provision of integrated, multidisciplinary rehabilitation services (8.2). The provision of one stop multidisciplinary clinics should not be implied as optional, please change 8.1 to state ‘provide’ instead of ‘consider providing’.
British Society for Rheumatology	Guideline	Rec 8.1	These section needs much more detail as to how patients should be triaged to different levels of support. It appears that much of the management is supportive akin to pain management programmes with an MDT approach and the concern is that there is little detail within the guidelines as to how this support should be delivered. Given the volume of referrals that services could be facing, there needs to be an acknowledgement as to how services can be set up and delivered, recognising that some patients could be supported via online resources, some patients in group settings and some 1:1 intervention. We already don’t have capacity within physiotherapy, occupational therapy and psychology to manage patients (eg for chronic pain and fatigue). There is also very limited access to psychology at present for patients with chronic disease so we are concerned that patients will be given unrealistic expectations of what can be offered. It will set up postcode lottery with better and worse support dependent on area. Very aware of the announcement of Long Covid Clinical network to be provided by secondary care with 40 clinics nationally, £10 million in funding from NHSE and predicted to have 60,000 patients. Given that the support is likely to be a rehab approach, we are concerned there is a lack of support for occupational therapists, physiotherapists, and psychologists that are going to be needed to support this patient cohort.
Chartered Society of Physiotherapy	Guideline	Rec 8.1	8.1: Please clarify whether these are COVID specific clinics. Clarify terminology, previously in 2.1 you use assessment of physical, cognitive, psychological, psychiatric symptoms and functional abilities. Could these clinics not be led by an experienced HCP other than a medical doctor?
Long Covid Wales	Guideline	Rec 8.1	Please remove the option of considering this provision; it should be worded as per section 8.2. This service should not be implied to be optional; one-stop multidisciplinary assessment clinics should carry just as much weight, if not more, as multidisciplinary rehabilitation services.

Stakeholder	Document	Section	Comments
British Society of Rehabilitation Medicine (BSRM)	Guideline	Rec 8.1	This is strongly supported. Involvement of Consultants in Rehabilitation Medicine in this process is essential & should be explicit, their roles are multi-facetted with experience & expertise in assessment & management of complex presentations. Rehabilitation provision in Wave 1 was (by necessity) reactive. For Wave 2 & beyond, we should be proactively identifying patients who may or will require rehabilitation from the point they step down from critical care, through the remainder of their hospital stay & have a Rehabilitation Prescription at the point of discharge. Processes similar to identification of Major Trauma patients' rehabilitation needs should be implemented, so that for the new cohort of most severely affected patients rehabilitation is a managed proactive process rather than a reactive process. From a research perspective, it would be useful to know whether this approach reduces the incidence &/impact of Post COVID syndrome
British Geriatric Society	Guideline	Rec 8.1	Will there always be a lead clinician in the specialist MDTs taking over responsibility for the patient's care? Will this be a doctor from chronic fatigue- syndrome/ ME or rehabilitation clinics? Is the workforce in this area large enough to fill posts in multiple MDTs across the country or will additional doctors need to be trained up? How will the difference in presentation in older adults affect the care which can be offered by the covid MDT, particularly with the specific needs of older people in mind, such as mobility barriers, restricted travel arrangements, cognitive impairment, sensory disturbances and potential need for a carer or relative to be present?
Oxford University Hospitals NHS FT	Guideline	Rec 8.1	again is assessment and rehab the same service - there are advantages in starting rehab sooner than later
Patient Safety Learning	Guideline	Rec 8.1	This guidance must cross reference to the recent issues NHSEI commissioning guidelines for the provisions of Long COVID clinics. Clinical assessment and rehabilitation services must be accessible to people regardless of their geographic location. It is important that those living in rural locations or at some distance from the Long COVID clinics are not disadvantaged.
British Society for Immunology	Guideline	Rec 8.1	This could be clearer and go further: one of the many problems for these patients is how to access the appropriate clinical team, especially if they have symptoms that straddle clinical specialties (e.g. respiratory and cognitive). Any recommendations need to signpost a potential care package that is multidisciplinary and joined up.

Stakeholder	Document	Section	Comments
The Society and College of Radiographers	Guideline	Rec 8.1	P12 line 8 This does not necessarily need to be led by a medical doctor, for example, have the stakeholders considered that an appropriately trained advanced practitioner nurse would be well placed to lead?
Long Covid SOS	Guideline	Rec 8.1	Isn't this what is being provided by NHSE? Or is this suggestion targeted at the devolved heath authorities?
ME Action UK	Guideline	Rec 8.1	“Consider providing one-stop multidisciplinary clinics for assessment of physical and mental health symptoms and further tests and investigations, led by a medical doctor” - We agree with this approach as long as patients are still referred to specialities outside of this clinic where appropriate. Overall it appears a sensible way to approach the challenges of different sub-groups of patients and the need for input from different specialities.
West Yorkshire and Harrogate Health and Care Partnership	Guideline	Rec 8.1	In line 8, it is unclear how this aligns with recommendations re. screening in section 4. It is important to ensure that the broad impact of symptoms and complexity are included here, ensuring that there is an MDT approach. Long Covid assessment clinics are already set up. It is unclear if this recommendation is referring to these clinics, or additional clinics in primary care.
Public Health England	Guideline	Rec 8.1	Line 5, P12 – For the ‘Service organisation’ section, we need to have a clear understanding of which level of organisation these are aimed at, clearly a lot of these cannot be coordinated solely though primary care
British Psychological Society	Guideline	Rec 8.1	We agree that provision of “one-stop” multidisciplinary clinics is helpful. Cognitive symptoms may be the predominant, or only symptom, for some patients. We therefore believe it is important to specify that these should also provide provide assessment of congitive symptoms i.e. amend to “physical, cognitive, and mental health symptoms”.
Scottish Intercollegiate Guidelines Network (SIGN) Council	Guideline	Rec 8.1	The advice and guidance in this section should reflect usual care unless the evidence is clear that alternative approaches result in improved outcomes. The guideline and panel acknowledged evidence is limited. The evidence is not clear in terms of what service organisation is best in the context of this syndrome and other requirements in the health service. For those reasons, in line with evidence, the first paragraph in service organisation should propose usual care: that is primary care services and referral to other options if available including multidisciplinary rehab services or specialist clinics. section 8.4 maybe better placed as the second paragraph

Stakeholder	Document	Section	Comments
Clinical Advisors to the Scottish Government (Clinical Guidance Cell, Professional Advisory Group)	Guideline	Rec 8.1	There is no evidence base yet for doing this. Should there not be an evaluation of the existing services first given the current pressures on health services? Does a patients GP not already fulfil this role? My recommendation is that any such clinics/services should be linked with research...Scotland is perfectly placed for such epidemiological resebackground-color:#f2f2f2;h, there is much to work out and whilst it may be an unfashionable observation, it is worth remembering that there are no accepted definitions for this although it has already been widely accepted as being "a thing", let alone how one might manage it. Perhaps there is something specific to COVID, although for many of us the concept of patients with persistent debilitating symptoms, often multiple, with normal investigations is one with which we are familiar - it may be that COVID is better at precipitating these symptoms, it may be there is something different about post COVID....or it may be its very similar to other post viral/insult syndromes. We will only find out with research, the immediate research that COVID triggered has been hugely impressive if at times overwhelming, this aspect should receive no lesser scientific scrutiny. There is also the risk/irony that if we divert resources to such services, we may exacerbate some of the inequalities people are highlighting. Surely this is dependent upon the size of the population requiring these services given that they would be focussed at the post-Covid group more- economics of scale may be an issue for some areas. Very wide range of symptoms. Perhaps initial MDT screening with referral criteria to support.
Association of British Neurologists	Guideline	Rec 8.1	• The neurological aspects need to be considered on their merits and the differential diagnosis explored if indicated. • There are a number of neurologists with a declared interest in COVID via enthusiasm for publications and research involvement. It may be that they are in a good position to join COVID MDTs if neurological input is needed and perhaps triage and advise. Given services are stretched already and we will be catching up, this may save a certain amount of referrals through to general neurology. We would not wish patients with post-other (or just ‘other’), and symptoms of comparable severity, to be sent even further back in the queue for rehab, psych input etc as a result of this statement of the obvious would be more comfortable if the text drew attention to the aspects of supporting post-Covid patients that are similar to support for post-anything, during this very challenging time A related point is that while I agree with the rationale that patients can be referred on whether or not they have had a positive Ab/Ag test, I also think it’s vital that evidence for prior infection to be ascertained – e.g. antibody testing is carried out even if this is on a research basis. While people with symptoms need appropriate management whatever, I think it’s important that we take the opportunity to define what is causally related to COVID infection per se to provide a rational evidence base for the future.

Stakeholder	Document	Section	Comments
Deaf Scotland	Guideline	Rec 8.1	Section 8. Is the process accessible? Will parts of extended teams be accessible, deaf/equality aware?
POTS UK	Guideline	Rec 8.1	Our experience with patients with PoTS is that assessment of complex patients with autonomic symptoms may require more than one appointment and also referral to specialist secondary or tertiary care services
Lifestyle, Exercise and Nutrition Improvement (LENI) Research Group	Guideline	Rec 8.2	We are not sure whether physiotherapy is appropriate for this clinical group - as clearly there is no supporting evidence. Furthermore, there is a clear trend to move away from chest physiotherapy even in groups (e..g, people with Cystic Fibrosis), where no direct alternative exist, with the NIHR willing to support research to explore the role of exercise etc. instead.
Faculty of Health Sciences, Oxford Brookes University	Guideline	Rec 8.2	It is unclear whether you are suggesting the development of a new, Covid 19 service (which would be a bad idea). If not, about the only service that would meet this description would be the local service that deals with patients after trauma, because these services see patients with an equally broad range of problems. In areas where there is not a local trauma service, then the local inpatient rehabilitation service is likely to manage patients with trauma and other broad-spectrum complex disorders and it would be appropriate for them to be seen, on an outpatient basis, by that service. You may not wish to make a specific recommendation that the local specialist rehabilitation service should be involved, but it is important that this is suggested as being the most likely currently existing available service able to meet the criteria set out. See: https://doi.org/10.1177/0269215520971145
Cardiff and Vale UHB	Guideline	Rec 8.2	yes but don't need a rehab medicine consultant as a core member, possibly only in tertiary centres..and we are one and have not seen any patients who have needed this level of care. Fewpost COVID patients have specialist rehab needs, the majority have multifaceted rehab needs which AHPs can ably provide.. and organisations can more easily pull together. Need in addition to add to your list dietetics and speech and language therapy
UK Doctors Long COVID Group	Guideline	Rec 8.2	As for 8.1
Royal College of Physicians	Guideline	Rec 8.2	It is suggested that speech and language therapy and dietician help may be helpful especially in view of anosmia and parosmia in COVID

Stakeholder	Document	Section	Comments
and Surgeons of Glasgow			
Asthma UK/British Lung Foundation	Guideline	Rec 8.2	It is currently not clear from this section if it is expected that new rehabilitation services will be provided, or people with long-covid given access to existing rehabilitation services such as pulmonary or rehab. There are likely to be significant capacity issues with community rehabilitation currently, exacerbated by the fact most services cannot be carried out face to face. Clear guidance on the design and delivery of long-covid rehabilitation services is essential.
Chartered Society of Physiotherapy	Guideline	Rec 8.2	8.2: Add dietitians and Speech and Language Therapists
Long Covid Wales	Guideline	Rec 8.2	Regarding lines 13-14, please see comments relating to section 3.3 – this has a similar disproportionate focus on lung pathology. For example, shortness of breath is commonly due to cardiac pathology.
British Society of Rehabilitation Medicine (BSRM)	Guideline	Rec 8.2	If local resources are taken into consideration for rehabilitation provision, this is potentially depriving patients of appropriate rehabilitation in localities where rehabilitation services are underprovided. Identification of local need will be adversely affected by an inadequate rehabilitation infrastructure, so may require development. There should be an additional section at this point on outcome measurement. Use of outcome measures that span all the components of the WHO International Classification of Functioning, Disability and Health should be used. Measures that capture body functions, activities, participation, personal perspectives, carers and healthcare professionals' views and quality of life Ref: Patel K, Straudi S, Yee Sien N, et al Applying the WHO ICF framework to the outcome measures used in the evaluation of long-term clinical outcomes in coronavirus outbreaks. Int J Environ Res Public Health. 2020; 17(18): E6476.
Patient Safety Learning	Guideline	Rec 8.2	As this guidance does not include what the specific symptoms are, this is far too general a statement. Need to include symptoms and specialist expertise that might be required/should be accessible. With many patients experiencing symptoms that prompt multi-organ concerns and evidence to show multi-organ damage, these multidisciplinary clinics should include specialists in these areas, for example cardiac, renal, gastrointestinal. It is important that, a physical assessment by a medical specialist is undertaken to identify and address any organ or multisystem dysfunction.
Public Health Scotland	Guideline	Rec 8.2	How will this be funded and supported?

Stakeholder	Document	Section	Comments
ME Action UK	Guideline	Rec 8.2	“Provide integrated, multidisciplinary rehabilitation services, based on local needs and resources, with a range of specialist skills, including expertise in treating fatigue” There are very significant changes made in the recent ME/CFS draft guideline from NICE, and we remain concerned that a significant paradigm shift is needed from some of those treating fatigue. We believe any expert in treating fatigue should have an understanding of the draft ME/CFS guideline and how to assess patients for ME/CFS, so as not to repeat the institutional harm that has been inflicted on people with ME/CFS.
National Guideline Centre	Guideline	Rec 8.2	In recommendation 8.2 the phrase “treating fatigue” is vague and of concern, in that there may be confusion between post -COVID-19 syndrome and ME/CFS. We have noted that recommendation 2.7 alerts to the possibility of post-COVID-19 syndrome but does not provide any distinguishing features from ME/CFS. For people who have symptoms consistent with ME/CFS, the recommendations in the draft ME/CFS guideline should be considered. We note that it is not yet known what the long-term prognosis of post -COVID-19 syndrome will be although some symptoms such as anosmia do seem to recover without intervention.
The Richmond Group of Charities	Guideline	Rec 8.2	When identifying components of a core team, the guidance should include the need to identify the potential role of voluntary sector and community organisations. It is not currently clear if it is expected that new rehabilitation services will be provided, or if people with long-covid will be given access to existing rehabilitation services. Given the significant pressures on, for example, community rehabilitation teams, it would therefore be helpful if the guidelines included a recommendation to assess the capacity of existing rehabilitation services to deliver this suggested integrated approach. Where capacity does not exist, appropriate resource should be put in place to ensure this.
British Thoracic Society	Guideline	Rec 8.2	Consider dieticians as part of this group.
Royal College of Nursing	Guideline	Rec 8.2	Need to include nursing e.g. nurses working in respiratory and primary care. Also should include wider nursing staff such as nursing support workforce e.g. Assistant Practitioners line 31- page 16 of 22: This should include religious and spiritual differences
Department of Health (Northern Ireland)	Guideline	Rec 8.2	SLTs should be listed as core members of the AHP rehab group given the proportion of patients that have trachea and post ICU swallow complications.

Managing the long-term effects of COVID-19
Targeted consultation on draft guideline
Comments table
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Stakeholder	Document	Section	Comments
West Yorkshire and Harrogate Health and Care Partnership	Guideline	Rec 8.2	There is no mention of social prescribing here – this would be helpful for some people.
CDH UK - The Congenital Diaphragmatic Hernia Charity	Guideline	Rec 8.2	Add Dietetics as an example to prompt Clinicians to recognise the importance of rehabilitating eating, appetite and smell and taste for example. This is even more crucial in patients with existing medical conditions whereby co-morbidities such as GERD, parenteral nutrition, feeding issues are present.
British Psychological Society	Guideline	Rec 8.2	“including treating fatigue….” is more appropriately worded “experience in the management of fatigue…”. 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.
Clinical Advisors to the Scottish Government (Clinical Guidance Cell, Professional Advisory Group)	Guideline	Rec 8.2	I find this statement unhelpful. based on existing resources and evidence base I am not sure that such as service is warranted until there is good data to support the additional resource.
Neurological Alliance	Guideline	Rec 8.2	add 'cognitive and behavioural' as follows: “with a range of specialist skills, including expertise in treating fatigue, cognitive, behavioural and respiratory symptoms, including shortness of breath” – this would be in recognition of the relatively high prevalence of these symptoms in post COVID19 syndrome studies, and the role of neuropsych services in supporting people with post COVID syndrome. Effective neuropsych and neurorehab services will be critical in providing effective support for ongoing COVID-19 syndrome and post covid syndrome - these are however chronically under-resourced currently, and require support.

Stakeholder	Document	Section	Comments
Association of British Neurologists	Guideline	Rec 8.2	Vital to refer those that require rehabilitation regardless of a positive test. also concerned about prioritising resources away from other conditions. It has been hard enough post-austerity in any case for patients with chronic neurological conditions to access the kind of resources mentioned in the document (MDT assessment, community therapy input, special clinics), and that whole patient group as far as I can tell have done very badly after the recent long period of confinement and isolation. So we are skeptical about a new referral pathway that prioritises resources for this rather loosely defined long-covid syndrome above those for patients with equally detrimental symptoms of other causes.
Royal College of Speech and Language Therapists (RCSLT)	Guideline	Rec 8.2	We strongly suggest adding speech and language therapists to the core team. Speech and language therapists (SLTs) working with individuals with long-COVID have identified common clinical presentations including cognitive communication, swallowing, voice, and respiratory needs, while the impact of stress and anxiety are also potential causes of muscle tension dysphonia. These clinical needs will be missed without the expertise of SLT input as part of the multidisciplinary team assessment and differential diagnosis, resulting in a lack of access to speech and language therapy intervention. We would like to emphasise the potential risks of not having speech and language therapy intervention for patients with respiratory/breathlessness issues, especially in exacerbating breathing problems and in vulnerable adults such as those with learning difficulties and dementia. Also, there are clear added benefits to having speech and language therapists involved with long-COVID patients presenting with cognitive communication problems, e.g. to help understand their condition and anxiety and access other services and interventions. Whilst we do not have hard evidence for the clinical benefits of speech and language therapy for long-Covid patients as yet, the profession is continuing to gather outcomes data for this new condition. In the absence of this data, we suggest the evidence papers listed below are used and referenced as they relate to some of the common symptoms identified by NICE and SLTs working with long COVID patients: • Chronic cough: https://www.cochrane.org/CD013067/AIRWAYS_speech-and-language-therapy-chronic-cough (Cochrane review) • Dysphonia: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6513026/ • Is voice therapy effective? Results of an RCT: https://www.bmj.com/content/323/7314/658 • Impact of SLT on anxiety related dysphonia: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5806435/ In addition, the papers linked below highlight clinical presentations that will continue to be seen in post-acute COVID patients and will become chronic presentations. These will therefore be part of the clinical presentations for patients with long-COVID who will require continued speech and language therapy input to support recovery. Please note: these papers were published after the NICE/SIGN inclusion/exclusion search was carried out 1) Prevalence of dysphagia identified in patients with covid

Stakeholder	Document	Section	Comments
			who were admitted to hospital (30% of total cohort in first phase needed dysphagia interventions) file:///C:/Users/paul.o/AppData/Local/Microsoft/Windows/INetCache/Content.Outlook/6X9ZHVLH/dysphagia_presentation_and_management_following_covid19_an_acute_care_tertiary_centre_experience.pdf 2) Frequency of tracheostomy insertion (over 50% of all patients admitted to ITU in the first wave), detailing the sequelae of dysphagia and upper airway issues that followed this file:///C:/Users/paul.o/AppData/Local/Microsoft/Windows/INetCache/Content.Outlook/6X9ZHVLH/covid%20trache.pdf 3) Prolonged Intubation and Tracheostomy in COVID-19 Survivors: https://healthmanagement.org/c/icu/issuearticle/prolonged-intubation-and-tracheostomy-in-covid-19-survivors As with all professions there are no long-term data sets available as this is still an emerging presentation. However, future research will require a multi-disciplinary approach and we strongly advise that is work includes speech and language therapists as a core member of the MDT. Outcome tools which will help support future data collection include the PICUPS tool (ICS) and the RCSLT Online Outcomes Tool (ROOT). Support services, e.g. ENT clinics, are not fully established to be able to work with SLTs to deliver services to this patient group. Having these in place would benefit SLT referral and patient care. In addition, given our acute information from the first phase, we can legitimately predict and extrapolate that people in the community will have also experienced dysphagia and upper airway issues, as we previously described, regardless of whether they were admitted to hospital as it was inherently linked to core COVID symptomatology. This community cohort will also require SLT input.
UK Doctors Long COVID Group	Guideline	Rec 8.3	There should be further emphasis on the development of clinical networks in primary/secondary/tertiary care to discuss patients, share expertise and conduct research. ? A national registry of patients should be developed to determine the prevalence of long COVID and impact on society, as well as collating information on symptoms, diagnoses and successful/proven management strategies.
Patient-Led Research for COVID-19	Guideline	Rec 8.3	Please see notes in general comments regarding our concern with the recommendation of a 1-minute sit-stand test.
National Guideline Centre	Guideline	Rec 8.3	Work on the ME/CFS guideline suggests that 1-minute sit to stand tests in people who have severe symptoms may be harmful and result in sequelae, such as worsening of symptoms. As this is not known in post -COVID-19 syndrome, it would be safer to put some warning around undertaking these tests in the community particularly if the ECG is not being monitored.

Stakeholder	Document	Section	Comments
British Psychological Society	Guideline	Rec 8.3	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. 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). 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.
Scottish Intercollegiate Guidelines Network (SIGN) Council	Guideline	Rec 8.3	Core team should include a "pharmacist" in the list. Respiratory and pain pharmacists can provide a range of specialist skills to support patients with long COVID.
Clinical Advisors to the Scottish Government (Clinical Guidance Cell, Professional Advisory Group)	Guideline	Rec 8.3	Surely this should be done as research with recommendation for this only passed on once data is scrutinised?
Long Covid Support Group	Guideline	Rec 8.3	Remove reference to 1-minute sit to stand or other exercise tests, as these can trigger worsening of symptoms.
Neurological Alliance	Guideline	Rec 8.3	It's absolutely critical that the pathways between primary, secondary and tertiary care recognise residual cognitive issues that may impact on successful return to activities (especially work). Suggest

Stakeholder	Document	Section	Comments
			this recommendation is therefore expanded to include ", breathlessness training and appropriate cognitive assessments"
Faculty of Health Sciences, Oxford Brookes University	Guideline	Rec 8.4	This illustrates the problem, but does not suggest any solution.
Cardiff and Vale UHB	Guideline	Rec 8.4	strongly agree, there must be an agreed pathway across the system, so GPs know what tests to do, what red flags to look for and when to refer to therapy MDT. Need to be clear what specialist services can offer, and how to access them appropriately to not over medical. Need to use alternatives to referral to gain secondary care advice eg. virtual consultation, e advice, virtual MDT. a big mistake would be to set up specialist secondary care services ..not needed.
Patient Advisory Group to the CFS/ME Research Collaborative (CMRC)	Guideline	Rec 8.4	Should services for patients who meet the diagnostic criteria for ME/CFS, and who do not have additional symptoms that are not part of the symptoms of ME/CFS, be coordinated with services for all other ME/CFS patients who have received their diagnosis often after other viral illnesses, thus enabling all these patients better access to appropriate care (as per draft ME/CFS guidelines)?
Carers Scotland	Guideline	Rec 8.4	This section should include local referral pathways to non public sector services, including community organisations that can provide important support to individuals and their carers. For example, local third sector organisations supporting people with mental health, carers centres, money advice etc.
Long Covid Wales	Guideline	Rec 8.4	As discussed in 8.1, emphasis here must be on multidisciplinary assessment, diagnosis, and treatment clinics. Rehabilitation and mental health care are secondary aspects of the care.
Patient Safety Learning	Guideline	Rec 8.4	This guidance must cross reference to NHSEI commissioning guidelines for the provisions of Long COVID clinics. There needs to be specific referral pathways developed for each body system effected to ensure physical pathologies are not missed. These pathways need to be based on current evidence, and regularly reviewed considering new data.
Public Health Scotland	Guideline	Rec 8.4	What is meant by ‘specialist services’ – wouldn’t these be the ‘multidisciplinary assessment clinics’ – is their funding for the ‘specialist mental health services’?

Stakeholder	Document	Section	Comments
BAME Health Collaborative (BHC)	Guideline	Rec 8.4	8.5 A suggested new recommendation under Service Organisation The rehabilitation pathway should reflect the needs of BAME patients by including: • Pastoral leadership • Religion/belief • Community Leads • Sexual Orientation / Gender Reassignment community links • Debunking cultural myths and treatments • Personal rehabilitative guide(hardcopy or digital) There must be a sustainable plan to increase the number of skilled rehabilitative counsellors, health and social care staff by offering COVID-19 training and self- management programs within BAME communities.
West Yorkshire and Harrogate Health and Care Partnership	Guideline	Rec 8.4	There needs to be reference to social care and VCSE sectors here.
British Psychological Society	Guideline	Rec 8.4	Agree
Clinical Advisors to the Scottish Government (Clinical Guidance Cell, Professional Advisory Group)	Guideline	Rec 8.4	These pathways already exist. The concern here is that post COVID patients might expect to be seen rapidly but unless there is additional resource they will be assessed on their clinical need within existing services. This may add to their anxiety. Important and I think more likely to work in less populated or low prevalence areas with regard post-Covid syndrome. Local underpinned by national guidance.
Neurological Alliance	Guideline	Rec 8.4	Suggest the inclusion of 'integrated' as follows "Agree integrated referral pathways..." - all too often, effective integration of services, particularly between mental and physical health services, does not happen in practice. A more explicit reference to the need for effective integration could help to change this, and recognise the need for truly multi-disciplinary care for people with post-covid syndrome (as is indicated throughout the draft guideline).

Stakeholder	Document	Section	Comments
Association of British Neurologists	Guideline	Rec 8.4	important that patients sent to secondary care for diagnosis can be returned to community care/primary care for management
Royal College of Speech and Language Therapists (RCSLT)	Guideline	Rec 8.4	What are their pathways for support for people with cognitive communication, swallowing, voice and respiratory needs if SLTs are not part of this core team? How will people access support in primary or community care? The term 'brain fog' is used three times in the guideline and is linked to cognitive processing delays, which includes language (spoken and written) and high level functioning especially for those returning to work. SLTs add huge value in supporting this rehabilitation pathway: Barman, A., Chatterjee, A., & Bhide, R. (2016). Cognitive Impairment and Rehabilitation Strategies After Traumatic Brain Injury. Indian journal of psychological medicine, 38(3), 172–181. https://doi.org/10.4103/0253-7176.183086 Sheila MacDonald & Catherine Wiseman-Hakes (2010) Knowledge translation in ABI rehabilitation: A model for consolidating and applying the evidence for cognitive-communication interventions, Brain Injury, 24:3, 486-508, DOI: 10.3109/02699050903518118
Faculty of Health Sciences, Oxford Brookes University	Guideline	Research Rec 1	It seems inappropriate to start looking for risk factors until there has been the development of some secure, evidence-based, and valid definition of the syndrome. This recommendation is putting the cart before the horse. Until we know what the syndrome is, it is difficult to establish risk factors or a trajectory.
Polymyalgia Rheumatica and Giant Cell Arteritis Scotland (PMR-GCA Scotland)	Guideline	Research Rec 1	Do pre-existing conditions or their treatments affect the likelihood of developing post COVID-19 syndrome?
UK Doctors Long COVID Group	Guideline	Research Rec 1	o Key recommendations for research should include an urgent need to understand the mechanism by which the SARS-COV2 virus causes prolonged illness, in particular addressing the three hypotheses for underlying pathogenesis: virus persistence, inflammatory damage (especially to the endothelium/autonomic nervous system), auto-immunity.

Stakeholder	Document	Section	Comments
The Poverty Alliance	Guideline	Research Rec 1	Risk factors should include type of employment as well as wider background such as household structure as well .
Chartered Society of Physiotherapy	Guideline	Research Rec 1	1. Risk factors for post-COVID-19 syndrome Suggest this is expanded or additional section on diagnosis of post-COVID-19 syndrome For example, Are there different subgroups of post-COVID-19 syndrome and how are they diagnosed
British Society of Rehabilitation Medicine (BSRM)	Guideline	Research Rec 1	Defining the clinical syndrome spectrum of long COVID Identifying the clusters/ phenotypes of presentation Exploring the underlying mechanisms involved in the presentation – Immunological/ Inflammatory/ Genetics/ Psychological correlates/ Metabolomics Role of gender – ?more common in females – why ?
UEA/Fifth Sense/The Norfolk Smell and Taste Clinic	Guideline	Research Rec 1	We recommend this is fed into the James Lind Alliance Priority Setting Partnership for Smell & Taste Disorders
British Geriatric Society	Guideline	Research Rec 1	The patient's sex is not mentioned in this section- more research needed on why women less likely to get severe covid than men and whether post covid symptoms are more prevalent in men or women.
Public Health Scotland	Guideline	Research Rec 1	The management guides above should include recommendations on capturing this information to help improve the knowledge bases and thus care.
Science for ME	Guideline	Research Rec 1	These are general comments on research, rather than specific to risk factors. Any research of Long Covid needs to avoid the problems that have beset most ME/CFS and Chronic Fatigue Research in the United Kingdom. These include a lack of objective outcomes, or poorly chosen objective outcomes with unblinded treatments; poorly characterised patient samples; inadequate recording of dropouts and harms; and a lack of, or inappropriate, controls. There must be research to understand the underlying biological mechanisms causing these persisting symptoms. Their aetiology and pathogenesis needs to be investigated, so that appropriate treatments can be found.
Long Covid SOS	Guideline	Research Rec 1	Do socioeconomic factors play a role? Under served communities and work insecure

Stakeholder	Document	Section	Comments
The Richmond Group of Charities	Guideline	Research Rec 1	An additional key research question which should be included is the impact of treatment and management decisions on the risk of developing long-covid. For example, could ventilation at an earlier stage reduce the incidence of long-covid?
West Yorkshire and Harrogate Health and Care Partnership	Guideline	Research Rec 1	There needs to be better recording of long Covid in primary care. This data can then be invaluable for research, e.g. understanding numbers, patient needs, risk factors etc. SNOMED codes need to be developed and implemented nationally.
Public Health England	Guideline	Research Rec 1	P13 – The very clear issue about any form of surveillance or research is that the definitions need to be clearly mandated. This allows a catch-all for anyone with confirmed or suspected (which could likely be from self-referral), and so the specificity of the case definition is likely to be very low. In practice for referral and treatment purposes this is fine, but for research purposes and extrapolation from people coming through the service it is paramount to differentiate those with confirmed disease to those with likely disease. There will be a large number of people with a constellation of clinical syndromes (CFS, fibromyalgia), and to lump everyone together as an a priori similar likelihood of having disease will significantly mask any ‘true’ signals. SNOMED codes should be created to allow for clear recording of different permutations i.e. ‘likely symptoms, confirmed PCR positive’ versus ‘unlikely symptoms, no diagnostic test’. In any recording system these groups should be clearly differentiated. There should be dedicated case report forms to ensure consistency of data collection within different clinical settings.
British Psychological Society	Guideline	Research Rec 1	We agree. Such research will clearly need to encompass both physical and psychological factors and proximal and distal influences.
Royal College of Paediatrics and Child Health	Guideline	Research Rec 1	Line 1: Risk factors for post-Covid syndrome: - consider an additional question on the risk of developing post Covid syndrome following PIMS.
Scottish Intercollegiate Guidelines Network	Guideline	Research Rec 1	What about inflammatory cytokines? These have been implicated in postviral chronic fatigue syndrome

Stakeholder	Document	Section	Comments
(SIGN) Council			
Mast Cell Action	Guideline	Research Rec 1	Look at the wider families of children suffering from Multisystem Inflammatory Syndrome, comorbidities and unusual symptoms.
Neurological Alliance	Guideline	Research Rec 1	Possibly for elsewhere in the recommendations: What is the prevalence and incidence of post C19 syndrome amongst people with learning difficulties? Does it differ compared from the prevalence and incidence in non-Learning Disability groups? (note, severity of LD needs to be factored in, as do other symptoms- bulbar, seizures etc) What is the prevalence and incidence of post C19 syndrome amongst people with neurological conditions? Does it differ compared to the prevalence and incidence in non-neuro groups? (note this would require a further breakdown to standard diagnoses, and measure of severity) Surveillance studies to monitor neurological sequalie are absolutely critical, and should be supported.
Association of British Neurologists	Guideline	Research Rec 1	There is a section on particular groups (those at greatest risk for various reasons) – I wonder whether those with occupational-acquired Covid (particularly those with high exposure, some of whom have experienced Covid for a second time) should be mentioned as a group too
Royal College of Speech and Language Therapists (RCSLT)	Guideline	Research Rec 1	Prognostic aspects - there is a need to understand the outcomes, in particular for people with various comorbidities such as dementia and learning difficulties Research should also target the economic impact of long-covid caused by inability to work. Research should look at disease burden - and the impact on the quality adjusted life year (QALYS) We suggest that prevalence of different symptoms in different patient groups is also needed in order to enable predictive modelling of interventions As we mentioned in an earlier comment, we suggest piloting the Intensive Care Society Rehabilitation PICUPS tool in long covid for screening of rehabilitation needs rather than reinventing the wheel. The PICUPS screening tool encompasses the whole Multidisciplinary team approach to rehabilitation and is newly developed in response to COVID-19 by the rehabilitation collaborative - please refer to this tool.
POTS UK	Guideline	Research Rec 1	Our experience with patients with PoTS suggests that understanding the pathophysiology of long-covid is likely to be key to understanding risk factors and elaborate whether there are different phenotypes of the syndrome requiring different approaches as a result
Engender	Guideline	Research Rec 2	We would note Gendered trends in rehabilitation and symptom patterns should be a central priority. For example, women are more likely to work in frontline roles, exacerbating their exposure to the virus, rely on public transport and provide care and childcare informally. In terms of work specifically, women are less likely than men to have jobs that ensure access even to statutory sick pay (70% of jobs below

Stakeholder	Document	Section	Comments
			SSP threshold are done by women) and are more likely to be employed on 0 hours or precarious contracts. Women's provision of care and childcare is significantly higher than men's and women continue to manage the majority of house and domestic work. Women are also less likely to be safe within their home, experience domestic abuse and quality, secure housing may be a concern. All of these factors are likely to affect rehabilitation and rest as well as access to clinical care and appointments. Flexibility must be central. It is also important to fill data and knowledge gaps in sex-differences in symptoms and outcomes to establish quality intervention needs. Initial data paints an uncertain pattern, but early ONS and NRS data did indicate that women were more likely to describe covid symptoms than men, more likely to test positive but that men have higher mortality outcomes. Emerging data now suggests that women are more likely to report long covid, but it is unclear why or whether this is statistically linked to a higher exposure / sickness rate. It will be important to continually measure and analyse data for particular groups, such as older women, Black and racialised women and disabled women.
Faculty of Health Sciences, Oxford Brookes University	Guideline	Research Rec 2	It is very unlikely that there will be any intervention that will manage all patients with equal efficacy, and the first question is misconceived. The intervention that is appropriate for a patient whose main problem is anxiety and distress will be different from the intervention that is appropriate for a patient with breathlessness, and again different from patients with other symptoms. Moreover, patients will have unique combinations of symptoms and will need different combinations of treatment. It is obvious that certain symptoms will require some specialist intervention. Breathlessness and demonstrated pulmonary problems will clearly require pulmonary rehabilitation, and this does not need further research. Similarly, high levels of anxiety will benefit from cognitive behavioural therapy and other similar therapies. This is a misconceived research priority. The third question about clusters of symptoms is also misconceived, and considers the syndrome is a uniform whole whereas it is, by definition, a collection of varied symptoms that will have varied treatments. There is a definite need to build a proper model of care. However, it is inappropriate to consider that this is restricted to Covid 19. There needs to be a wholesale review of the organisation of rehabilitation services, and this need is demonstrated by Covid 19. Trying to solve Covid-19 in isolation will worsen the current chaotic state of rehabilitation services. See: https://doi.org/10.1177/0269215520971145 It is appropriate to consider the role of exercise, because exercise has general benefits across almost all symptoms. However, the research needs to recognise that no single exercise prescription will be appropriate, and that exercise will need to be tailored to the needs and requirements of the individual patient. Research into what policy or mechanism of increasing exercise would be appropriate.

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Patient Advisory Group to the CFS/ME Research Collaborative (CMRC)	Guideline	Research Rec 2	It is vital that a mechanism is put in place so that patients can independently report any detrimental effects of exercise interventions. Patients who meet the diagnostic criteria for ME/CFS must be fully informed of the risk of harm associated with graded exercise therapy and similar treatments, as repeatedly reported by ME/CFS patients.
Carers Scotland	Guideline	Research Rec 2	We would suggest in line with other research, for example the benefits of training carers of people who have had a stroke, (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC406319/), research is undertaken on the impact of the involvement of an unpaid carer or family in support an individual with post COVID has on recovery or length of experiencing the symptoms of post COVID. This would consider the benefits of involving carers and families in supporting an individual to, for example, self manage their symptoms, could have.
UK Doctors Long COVID Group	Guideline	Research Rec 2	o Include research on the safety of vaccines in patients with long COVID, including the COVID vaccination, as once data is available this should be included within the guidance.
Insight IAPT	Guideline	Research Rec 2	there is a lack of connection to other NICE guidance associated with psychological aspect of treatment for Post COVID-19 syndrome. current IAPT (improving access to psychological therapies) provide psychological therapy in accordance with the following NICE guidelines: Depression in adults with a chronic physical health problem: recognition and management Clinical guideline [CG91 Common mental health problems: identification and pathways to care Clinical guideline [CG123] Mental wellbeing at work Public health guideline [PH22] Post-traumatic stress disorder NICE guideline [NG116] Generalised anxiety disorder and panic disorder in adults: management Clinical guideline [CG113] Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): diagnosis and management Clinical guideline [CG53] there is evidence of the positive impact on physical health by introducing IAPT evidence based therapy to treat conditions in an integrated IAPT service which include: Cardiac Conditions Respiratory Conditions Diabetes Medically Unexplained Symptoms Fibromyalgia Chronic Pain Irritable Bowel Syndrome Chronic Fatigue Syndrome some of these symptoms/conditions are also showing in Post COVID-19 syndrome so treatment within IAPT services would be of benefit to those in recovery. sessions would be longer for these patients (typically up to 18 sessions). https://www.rcpsych.ac.uk/docs/default-source/improving-care/nccmh/iapt/nccmh-iapt-ltc-full-implementation-guidance.pdf?sfvrsn=de824ea4_4 https://www.cambridge.org/core/journals/the-

Stakeholder	Document	Section	Comments
			cognitive-behaviour-therapist/article/successful-impact-of-adapting-cbt-in-iapt-for-people-with-complex-longterm-physical-health-conditions/6AB3BC95E7EA54B19266191A1BCDBFF8 Developing Services for Patients with Depression or Anxiety in the Context of Long-term Physical Health Conditions and Medically Unexplained Symptoms: Evaluation of an IAPT Pathfinder Site Kellett, Stephen; Webb, Kimberley; Wilkinson, Nic; Bliss, Paul; Ayers, Tom; et al.Behavioural and Cognitive Psychotherapy; Cambridge Vol. 44, Iss. 5, (Sep 2016): 553-567 for those who may be off sick due to post COVID-19 syndrome would also benefit from employment support that is now integrated into IAPT services: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5051977/ any services established need to demonstrate Parity of Esteem utilising the validated screening tools for those experiencing psychological distress. These validated tools include GAD7, PHQ9, Phobia ratings and Impact of Events scale (IES) for PTSD for those who spent time in Intensive Care.
Royal College of Physicians and Surgeons of Glasgow	Guideline	Research Rec 2	The research questions do not appear to draw on the long experience with other post infectious and multisystem disorders such as post-EBV, MERS, ARDS. Natural history studies should explore similarities and differences to those so that therapeutic techniques already in use can be applied.
The Poverty Alliance	Guideline	Research Rec 2	This should take account of barriers household face accessing support for example in deprived communities waiting times for appointments for GP's etc can be longer.
NICE GP Reference Panel	Guideline	Research Rec 2	Please can we have a specific recommendation for interventions that can be delivered in primary care. My worry is that all the research focus will be on secondary care or specialist level clinics, when the vast majority of people will be dealt with in Primary Care and we desperately need answers to what does, or does not work in primary care populations
Chartered Society of Physiotherapy	Guideline	Research Rec 2	. Interventions for post-COVID-19 syndrome Line 8/9 suggest: What is the efficacy and clinical effectiveness of interventions for treating and managing specific symptom(s) of post-COVID-19 syndrome Line 10/11 suggest: Do any symptoms or patterns of symptom behaviour predict the need for specific interventions, specialist or post-COVID-19 syndrome rehabilitation? Line 12/13 suggest: Are there clusters of symptoms and/or patterns of symptom behaviour that identify response to interventions for post-COVID-19 syndrome Line 14-16 include efficacy as well as clinical effectiveness Line 17-18 suggest Does the timing of interventions have an effect on the outcome of rehabitiation? Other recommendations for research Line 11 suggest expanding this to Validated tools for screening and assessment of post-COVID-19 syndrome and evaluating the outcome of management and rehabilitation

Stakeholder	Document	Section	Comments
ICUsteps Peer Support Charity	Guideline	Research Rec 2	Consider discussing with the patient joining a NIHR study such as Rehabilitation Exercise and psycholoGical support After covid-19 InfectioN (REGAIN) https://warwick.ac.uk/fac/sci/med/research/ctu/trials/regain.
Long Covid Wales	Guideline	Research Rec 2	Regarding lines 17-18: Exercise has been found not to be safe, and is currently cautioned against in the management of Long COVID. The large patient community is in unison regarding any form of graded exercise being the direct cause of setbacks, and peer advice is therefore to avoid graded exercise. Focus is instead on an initial period of convalescence, often longer than most patients would think, followed by gentle pacing. This section needs to be reworded to reflect this existing insight into disease management. Furthermore, this section must comment on post-exertional malaise, as well as dangers with exertion if a thorough systems review with appropriate investigations have not been carried out (please see comments to section 2.2 for an example list of conditions associated with COVID-19). We would strongly recommend that there be data collection and research into whether OTC vitamins and supplements are helpful, or not. Such potentially large natural experiments could well provide useful answers quickly. Not quite an intervention, however research recommendations must include gaining an understanding of the underlying pathophysiology of Long COVID; it is not appropriate to have left this out. This can for example focus on the current hypotheses, as discussed in the comments to the introduction section (general comments), of viral persistence in immune-privileged sites, excessive inflammatory response (especially pan-endotheliolitis and inflammatory damage to the autonomic system), or autoimmunity. Research should also look at the difference in prevalence of Long COVID between hospitalised and non-hospitalised patients. Reports from patient forums are strongly indicative of Long COVID being prevalent to a much greater extent in the non-hospitalised cohort. If this hypothesis was proven to be true, research must look at the underlying reasons for this. For example, does early oxygen supplementation, steroid treatment, or simply a higher level of convalescence due to nursing care affect long term outcome? Hormonal and gynaecological aspects of Long COVID are currently a gap in proposed research. For example, are women of menopausal age more at risk of Long COVID because of their changing hormonal state? Do symptoms of Long COVID vary with menstrual cycle?
UEA/Fifth Sense/The Norfolk Smell and Taste Clinic	Guideline	Research Rec 2	We recommend this is fed into the James Lind Alliance Priority Setting Partnership for Smell & Taste Disorders

Stakeholder	Document	Section	Comments
British Geriatric Society	Guideline	Research Rec 2	Does being on HRT have any bearing on the severity of covid or ongoing symptoms of covid after 4 weeks?
Oxford University Hospitals NHS FT	Guideline	Research Rec 2	We definitely need research on 'Does early exercise rehabilitation assist in improving symptoms of post-COVID-19 17 syndrome?'
Patient Safety Learning	Guideline	Research Rec 2	How does early referral to clinical specialists' impact on patient outcomes?
Public Health Scotland	Guideline	Research Rec 2	The management guides above should include recommendations on capturing this information to help improve the knowledge bases and thus care.
Science for ME	Guideline	Research Rec 2	Suggest "Does active discouragement of early exercise assist in improving symptoms of post-COVID-19 syndrome?". Please also refer to the draft ME/CFS guideline and its supporting documents that assesses the existing literature on Graded Exercise and CBT for ME/CFS, and finds them to be all of Low or Very Low quality evidence, given that this literature might be used as justification for exploring these interventions in people with Long Covid.
Long Covid SOS	Guideline	Research Rec 2	Exercise rehabilatation - Anecdotally from the Body Politic Covid19 Slack group a lot of people were fit and athletic before long covid. Exercise could be one of the predisposing factors. Does there need to be a research question on what effective convalescence looks like? - Or does it cause disease progression?
ME Action UK	Guideline	Research Rec 2	"What are the most clinically effective interventions for managing post-COVID-19 syndrome?" - resebackground-color:#f2f2f2;h on this question is required - "Does rest assist in improving symptoms and outcomes?"
University College London Hospital	Guideline	Research Rec 2	Does early autonomic management plan including autonomic rehabilitation assist in improving symptoms of post-COVID-19 17 syndrome?
British Psychological Society	Guideline	Research Rec 2	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. 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

Stakeholder	Document	Section	Comments
			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 et al 2011) and should be included as a priority area in Post COVID-19 research. An important aspect of intervention evaluation will be assessing the effect of early intervention, including provision of information and self-management advice, on recovery. Intervention trials will also need to carefully consider the effects of co-morbidity of other physical and mental health conditions. 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? Psychological medicine, 41(5), pp.1099–1107.
Long Covid Support Group	Guideline	Research Rec 2	Lines 8-9: Include consideration of potential early interventions that might prevent people from developing Long Covid (e.g. steroids, antiviral medication). Lines 17-18: Why is exercise singled out as a possible early intervention when it is known by people with Long Covid to cause significant worsening symptoms among many people? Why aren't other potential early interventions mentioned? (e.g. steroids, antiviral medication)
Neurological Alliance	Guideline	Research Rec 2	Line 14 – this could more explicitly include an indication of the healthcare professional skill mix required to provide integrated services? Additional question: What are the most clinically effective interventions for managing post C19 syndrome in people with one or more neurological condition? (To include a subset of neurological conditions, recognising the range and complexity of this group).
Faculty of Health Sciences, Oxford Brookes University	Guideline	Research Rec 3	This question has two components. The first is a scientific question as to whether or not genetic or other characteristics associated with particular racial groups leads to a different response to the Covid virus. The second question is whether people who are in some form of ethnic minority are more at risk on account of their associated socio-economic deprivation and discrimination in service delivery. One is a biological question, the other a sociological question.
Royal College of General Practice England, Wales, Scotland and Ireland	Guideline	Research Rec 3	We are concerned that this limits the epidemiological question to BAME communities only and would propose a wider question asking about the epidemiology focusing on all disadvantaged groups.

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Targeted consultation on draft guideline
Comments table
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Stakeholder	Document	Section	Comments
UEA/Fifth Sense/The Norfolk Smell and Taste Clinic	Guideline	Research Rec 3	We recommend this is fed into the James Lind Alliance Priority Setting Partnership for Smell & Taste Disorders
Patient-Led Research for COVID-19	Guideline	Research Rec 3	We appreciate the attention to researching Long COVID in Black, Asian and minority ethnic groups as we view this as a top priority issue. Research on post-viral illnesses prior to COVID-19 indicates there are racial disparities affecting these patients that must be acknowledged and addressed in research. A recent 7-year prevalence study on ME/CFS showed there are barriers for minority groups in receiving a diagnosis of ME/CFS as well as higher prevalence among Black and Latinx youth compared to Caucasian peers. (https://link.springer.com/article/10.1007/s10566-019-09543-3)
Public Health Scotland	Guideline	Research Rec 3	The management guides above should include recommendations on capturing this information to help improve the knowledge bases and thus care.
The Richmond Group of Charities	Guideline	Research Rec 3	Assessing the impact of other protected characteristics should be included alongside age and ethnicity. For example, it would be helpful to know whether there is a disproportionate impact on a certain sex or people with certain long-term physical or mental health conditions including the risk and trajectory of long-covid for those who are experiencing co-morbidities and multi-morbidities.
British Psychological Society	Guideline	Research Rec 3	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. 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.
Royal College of Paediatrics and Child Health	Guideline	Research Rec 3	Post covid-19 syndrome in BAME communities: - consider including ‘does prevalence and incidence differ in children and adolescents from BAME groups as suggested from acute data e.g. Harman et al Ethnicity and Covid-19 in children with co-morbitdities. Lancet Child Adolesc Health. 2020 Jul;4(7):e24-e25. doi: 10.1016/S2352-4642(20)30167-X.
MSD Ltd	Guideline	Research Rec 3	MSD suggests that this research objective should also evaluate any differences for ethnic minorities versus other racial groups in ability to access ongoing symptomatic COVID-19 or post-COVID-19 syndrome services, as well as whether the baseline factors impacting trajectory are the same as for other racial groups.

Stakeholder	Document	Section	Comments
Long Covid Support Group	Guideline	Research Rec 3	Lines 19-22. Combine these questions with those on Page 14, lines 5-8 and rephrase to be more open. For example: What are the prevalence and incidence of Long Covid, and can data be disaggregated by age group, sex, ethnicity, socio economic background, employment status, co-morbidity? To what extent do symptoms vary across these segments?
Association of British Neurologists	Guideline	Research Rec 3	There is a section on particular groups (those at greatest risk for various reasons) – I wonder whether those with occupational-acquired Covid (particularly those with high exposure, some of whom have experienced Covid for a second time) should be mentioned as a group too
Faculty of Health Sciences, Oxford Brookes University	Guideline	Research Other Rec 1	All of these recommendations suffer the same fundamental weakness, namely the lack of any appropriate definition of what constitutes the syndrome. Until this is developed, and it will take a year or two to develop it at a minimum, the other projects become pointless.
British Psychological Society	Guideline	Research Other Rec 1	Agree
Association of British Neurologists	Guideline	Research Other Rec 1	There is a section on particular groups (those at greatest risk for various reasons) – I wonder whether those with occupational-acquired Covid (particularly those with high exposure, some of whom have experienced Covid for a second time) should be mentioned as a group too
Royal College of Speech and Language Therapists (RCSLT)	Guideline	Research Other Rec 1	People who need extra support with communication could be supported by SLT as well as family members and carers. We think it's important to specify that those with learning disabilities are considered as they have been found to have worse outcomes following COVID, although cause not specified. Please evidence below: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/933612/COVID-19__learning_disabilities_mortality_report.pdf
Faculty of Health Sciences, Oxford Brookes University	Guideline	Research Other Rec 2	All of these recommendations suffer the same fundamental weakness, namely the lack of any appropriate definition of what constitutes the syndrome. Until this is developed, and it will take a year or two to develop it at a minimum, the other projects become pointless.

Stakeholder	Document	Section	Comments
Patient Advisory Group to the CFS/ME Research Collaborative (CMRC)	Guideline	Research Other Rec 2	Research into the similarities and differences between post-COVID syndrome and ME/CFS (a serious illness often triggered by a range of viral illnesses and with many overlapping symptoms) is required. This would benefit both patient populations, and lead to a better understanding of post-viral illness in general. An important aspect to look at is the relationship between long-COVID, ME/CFS and other post-viral issues. Long-term observation studies would also help understand how the issues evolve and the quantify the proportion of long-COVID patients who end up with long-term issues.
Insight IAPT	Guideline	Research Other Rec 2	older adults are under-represented within psychological therapy services as very often they do not identify in psychological distress associated with their physical health condition so this population of patients may need proactive engagement, especially in those whom have spent a period of time in hospital. Integrated care pathways need to demonstrate parity of esteem
Long Covid Wales	Guideline	Research Other Rec 2	Research must focus on defining the illness – in all age groups – , including identifying which conditions may be associated with Long COVID (see comments to section 2.2 for a list of examples of currently known conditions).
The Royal College of Obstetricians & Gynaecologists	Guideline	Research Other Rec 2	Line 5-6. We would ask the developers to include pregnant women in this subgroup analysis.
British Geriatric Society	Guideline	Research Other Rec 2	There needs to be a better means of improving detection of cases of older patients in the community with atypical symptoms.
British Psychological Society	Guideline	Research Other Rec 2	Agree
Royal College of Paediatrics and Child Health	Guideline	Research Other Rec 2	Line 5 – consider an additional question such as can post Covid-19 syndrome be pre-ceded by asymptomatic Covid-19 infection.

Stakeholder	Document	Section	Comments
Clinical Advisors to the Scottish Government (Clinical Guidance Cell, Professional Advisory Group)	Guideline	Research Other Rec 2	The document makes two excellent points. 1. “What symptoms do children, young people and older people with suspected post-7 COVID-19 syndrome present with?” (page 14 line 7) 2. The panel highlighted that some people, including children and older 20 people in particular, may report different symptoms to those most commonly seen in 21 other age groups (page 16 line 20) Consistent with the two above points there seems to be no long COVID “on the radar” of acute services. However the apparent disconnect between severity of initial infection and long COVID may mean that there will be a surge in long COVID even though there has been very little morbidity from COVID. Paediatricians in Scotland are already seeing a rise in CAMHS illnesses, and it may prove hard to distinguish between “ME” and “long COVID”. At this point in time, where we are not sure about the quantity and quality of long COVID in children and young people, in it would be useful for Government to consider investment into the often ad hoc “ME” services available in some boards. My only comment is that children and older people are grouped together in a number of paragraphs and sections. This does not read well and I suggest they are separated out and referred to individually.
Long Covid Support Group	Guideline	Research Other Rec 2	Combine this question with those on Page 13, lines 19-22 and rephrase to be more open. For example: What are the prevalence and incidence of Long Covid, and can data be disaggregated by age group, sex, ethnicity, socio economic background, employment status, co-morbidity? To what extent do symptoms vary across these segments?
Neurological Alliance	Guideline	Research Other Rec 2	Possibly for elsewhere in the recommendations: What are the most likely symptoms of people living with post C19 syndrome and one or more neurological condition? What is the clinical impact of post COVID syndrome on existing neurological conditions?
Faculty of Occupational Medicine	Guideline	ResearchOtherRec3	What are the main symptoms that prevent people from returning to work
Faculty of Health Sciences, Oxford Brookes University	Guideline	Research Other Rec 3	All of these recommendations suffer the same fundamental weakness, namely the lack of any appropriate definition of what constitutes the syndrome. Until this is developed, and it will take a year or two to develop it at a minimum, the other projects become pointless.

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Patient Advisory Group to the CFS/ME Research Collaborative (CMRC)	Guideline	Research Other Rec 3	Research into the similarities and differences between post-COVID syndrome and ME/CFS (a serious illness often triggered by a range of viral illnesses and with many overlapping symptoms) is required. This would benefit both patient populations, and lead to a better understanding of post-viral illness in general. An important aspect to look at is the relationship between long-COVID, ME/CFS and other post-viral issues. Long-term observation studies would also help understand how the issues evolve and the quantify the proportion of long-COVID patients who end up with long-term issues.
UK Doctors Long COVID Group	Guideline	Research Other Rec 3	Include an urgent need to understand the mechanism by which the SARS-COV2 virus causes prolonged illness, in particular addressing the three hypotheses for underlying pathogenesis: virus persistence, inflammatory damage (especially to the endothelium/autonomic nervous system), auto-immunity
Royal College of Physicians and Surgeons of Glasgow	Guideline	Research Other Rec 3	The research questions do not appear to draw on the long experience with other post infectious and multisystem disorders such as post-EBV, MERS, ARDS. Natural history studies should explore similarities and differences to those so that therapeutic techniques already in use can be applied.
Long Covid Wales	Guideline	Research Other Rec 3	Not quite relevant to natural history of Long COVID, however research recommendations must include the direct and ongoing involvement of patient groups. Offering patients with Long COVID the possibility of contributing to research on this novel condition can be empowering and therapeutic in itself, as well as aid in achieving more accurate and targeted projects. We accept we may have a condition for which there is currently no prognosis and no specific therapy, but we have direct vested interest in understanding this disease and helping to develop potential treatments. This could easily be facilitated through multi-disciplinary long COVID clinics, especially in teaching hospitals, which should, of course, regard it as a primary responsibility in any case.
British Society of Rehabilitation Medicine (BSRM)	Guideline	Research Other Rec 3	What is the impact of MDT rehabilitation?
The Royal College of Obstetricians	Guideline	Research Other Rec 3	We would urge pregnancy status and the gestational age of pregnant women, to be recorded in all studies of childbearing age. This would enable subgroup analysis for pregnancy, if required in the future.

Stakeholder	Document	Section	Comments
& Gynaecologists			
UEA/Fifth Sense/The Norfolk Smell and Taste Clinic	Guideline	Research Other Rec 3	reference the GCCR publications by Parma et al
Public Health Scotland	Guideline	Research Other Rec 3	COVID-19 is a new infection and the evidence base on the long term effects has not had time to develop. This could be made clearer in the guidance. It may be difficult to invest in services for the long term when the long term effects of COVID are not yet understood. The psychological impact of COVID needs to be explored at an individual and population level. The impact of severe illness and time spent on ICU should be differentiated from mild COVID resulting in post COVID syndrome.
National Guideline Centre	Guideline	Research Other Rec 3	Long term follow-up with a post-COVID-19 registry on a national basis is essential to understand the long-term sequelae of COVID-19 and to understand how different interventions affect outcomes. While developing the ME/CFS guidelines we were repeatedly confronted by the lack of high-quality evidence and a lack of long-term monitoring of outcomes. COVID-19 provides a unique research opportunity epidemiologically and we would recommend that every patient is offered the opportunity for their data to be entered on a national database so that they can be monitored long term. Such a database would be an important research investment over time and would allow the UK to continue to be at the forefront of COVID-19 related innovation.
British Psychological Society	Guideline	Research Other Rec 3	Agree
Long Covid Support Group	Guideline	Research Other Rec 3	Replace post-COVID-19 syndrome with 'COVID-19' Key areas people in our Long Covid Support Group would like research to cover: What is the cause of Long Term Covid-19 symptoms? Are symptoms due to viral persistence - are people still infectious if they continue to be symptomatic? Are symptoms related to ongoing inflammation? Are symptoms due to organ damage? What are the therapeutic options for people with Long Covid? What new diagnostic modalities are required to assess ongoing symptoms? In what circumstances is exercise beneficial or detrimental? Comments on Excluded and Included Papers: Included Papers: ZOE, App and COVID Symptom Study How long

Stakeholder	Document	Section	Comments
			does COVID-19 last? COVID Symptom Study The ZOE/KCL app data on Long Covid is unreliable for the following reasons 1. Long Covid has been defined by the investigators with no patient involvement, therefore, it is not underpinned by any physical reality as experienced by patients. For example, they define Long Covid as having five symptoms or more. This is, patently, ludicrous. 2. People are deemed to have recovered if they have reported 5 days for more with no symptoms. This ignores the relapsing-remitting nature of Long Covid. Recovery must be defined by patients, it is meaningless for investigators who have never actually spoken to a patient to decide what recovery looks like. Any study which manages to not discover that Long Covid is relapsing-remitting, one of the main defining features as experienced by patients, then it’s a signal that there’s something badly flawed with their methodology. 3. Extreme bias in sampling. Many people with Long Covid gave up on the Zoe app because it was so user unfriendly. Because of the extremely limited list of symptoms, there was a burden on users to, daily, list all of their other symptoms. 4. What the ZOE/KCL app has, in fact, discovered is that middle aged white women are the demographic which is most likely to stick at it and keep using their app. The ZOE/KCL app was designed to be a sentinel for infectious outbreaks, which it does well. They extended the scope into Long Covid without amending the study design in order to achieve that new aim. A mathematical model must be compared with reality in order to have validity. Zoe have failed to do this final sense checking step. It is a poor tool to investigate Long Covid and it is unfortunate that it has had so much influence. Excluded papers Many papers were excluded for reasons which we don’t understand when they could speak to the question of the natural history of the illness. Why are pathophysiology/mechanism papers excluded? Surely an understanding of the mechanisms are crucial for understanding the natural history of the condition? The following papers have been excluded on the basis that the population is not Covid specific, however, this is not the case. All of these papers are in Covid patients Puntmann, Valentina O, Carerj, M Ludovica, Wieters, Imke et al. (2020) Outcomes of Cardiovascular Magnetic Resonance Imaging in Patients Recently Recovered From Coronavirus Disease 2019 (COVID-19). JAMA cardiology Salehi, Sana; Reddy, Sravanthi; Gholamrezanezhad, Ali (2020) Long-term Pulmonary Consequences of Coronavirus Disease 2019 (COVID-19): What We Know and What to Expect. Journal of Thoracic Imaging 35(4): w87 Fardman A, Oren D, Berkovitch A, Segev A, Levy Y, Beigel R, Matetzky S (2020) Post Covid-19 acute myocardial infarction rebound. Canadian journal of cardiology This was wrongly excluded as being an inpatient cohort when it is not, it is an outpatient cohort O'Keefe, James B., Tong, Elizabeth J., O'Keefe, Ghazala A. Datoo et al. (2020) Predictors of disease duration and symptom course of outpatients with acute covid-19: a retrospective cohort study. medRxiv: 2020060520123471 Why is this

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			case series being excluded when it seems highly relevant? Garrigues, Eve, Janvier, Paul, Kherabi, Yousra et al. (2020) Post-discharge persistent symptoms and health-related quality of life after hospitalization for COVID-19. Journal of Infection - Study design: Case series (Prevalence) The following papers have been excluded on the grounds that they relate to acute Covid, however, they are not irrelevant to Long Covid as they describe sequelae which could manifest as Long Covid. Data from the Netherlands shows that the symptom profile of Long Covid is not different in most respects those who were hospitalised and those who were not. There is a fundamental mistake in regarding those who did not enter hospitals for SARS-like symptoms as though they had a different disease from those who did. The ability to access secondary healthcare should not be used as a diagnostic criterion, especially in respect of non-pulmonary symptoms. Just because you didn't manage to get admitted to hospital for respiratory symptoms doesn't mean that your neuro, GI, skin, cardiac or other symptoms are not as severe as those who were admitted. Or, for that matter, respiratory. Many people with Long Covid suffered at home with severe breathing difficulties but were unable to access healthcare due to the restrictions in place because of the pandemic. Just because they didn't die, doesn't mean that they didn't also have severe symptoms. Many people with Long Covid have been through the experience of struggling so much with their breathing that they were afraid to go to sleep at night in case they didn't wake up. The assumption that we all just had something which was no worse than a bad cold is false. We would request a review of all of the papers which were excluded on the grounds of pertaining to Acute Covid-19, but in particular, those below. Reason for exclusion Population Acute Covid-19 Ahmad, Imran and Rathore, Farooq Azam (2020) Neurological manifestations and complications of COVID-19: A literature review. Journal of clinical neuroscience : official journal of the Neurosurgical Society of Australasia 77: 8-12 - Population: Acute Covid-19 Demertzis, Zachary D, Dagher, Carina, Malette, Kelly M et al. (2020) Cardiac sequelae of novel coronavirus disease 2019 (COVID-19): a clinical case series. European heart journal. Case reports 4(fi1): 1-6 - Population: Acute Covid-19 Denina, Marco, Pruccoli, Giulia, Scolfaro, Carlo et al. (2020) Sequelae of COVID-19 in Hospitalized Children: A 4-Months Follow-Up. The Pediatric infectious disease journal - Population: Acute Covid-19 Elsayed, Sarah M, Reddy, Mithun K, Murthy, Pooja M et al. (2020) The Possibility and Cause of Relapse After Previously Recovering From COVID-19: A Systematic Review. Cureus 12(9): e10264 - Population: Acute Covid-19 Sally J, Singh, Amy C, Barradell, Neil J, Greening et al. (2020) The British Thoracic Society survey of rehabilitation to support recovery of the Post Covid -19 population. medRxiv - Population: Acute Covid-19 Shaw, Brian; Daskareh, Mahyar; Gholamrezanezhad, Ali (2020) The lingering manifestations of COVID-19 during and after convalescence: update on long-term pulmonary

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			consequences of coronavirus disease 2019 (COVID-19). La Radiologia medica - Population: Acute Covid-19 Tong, Jane Y., Wong, Amanda, Zhu, Daniel et al. (2020) The Prevalence of Olfactory and Gustatory Dysfunction in COVID-19 Patients: A Systematic Review and Meta-analysis:. Otolaryngology–Head and Neck Surgery - Population: Acute Covid-19 Touisserkani, Sam K and Ayatollahi, Azin (2020) Oral Corticosteroid Relieves Post-COVID-19 Anosmia in a 35-Year-Old Patient. Case reports in otolaryngology 2020: 5892047 - Population: Acute Covid-19 Vaira, Luigi Angelo, Hopkins, Claire, Salzano, Giovanni et al. (2020) Olfactory and gustatory function impairment in COVID-19 patients: Italian objective multicenter-study. Head & neck 42(7): 1560-1569 - Population: Acute Covid-19 Vitale, Jacopo Antonino, Perazzo, Paolo, Silingardi, Marina et al. (2020) Is disruption of sleep quality a consequence of severe Covid-19 infection? A case-series examination. Chronobiology international 37(7): 1110-1114 - Population: Acute Covid-19 Wang, X, Xu, H, Jiang, H et al. (2020) Clinical features and outcomes of discharged coronavirus disease 2019 patients: a prospective cohort study. QJM : monthly journal of the Association of Physicians 113(9): 657-665 - Population: Acute Covid-19 Wenting, Angela, Gruters, Angelique, van Os, Yindee et al. (2020) COVID-19 Neurological Manifestations and Underlying Mechanisms: A Scoping Review. Frontiers in psychiatry 11: 860 - Population: Acute Covid-19 The following papers should be included COVID-19-associated olfactory dysfunction reveals SARS-CoV-2 neuroinvasion and persistence in the olfactory system https://www.biorxiv.org/content/10.1101/2020.11.18.388819v1?fbclid=IwAR0pP5Rm5fNuayF8xok7msnhSAzITu379npmCTYMMQfnMY_NkLHiH6BDwbI Evolution of Antibody Immunity to SARS-CoV-2 https://www.biorxiv.org/content/10.1101/2020.11.03.367391v1?fbclid=IwAR22ra2Rcums8vDtHkHgYS9DbVpkNrCP8YSMAayHLxkg2K93rvEyozWgm5E Puntmann, V. O. et al. Outcomes of Cardiovascular Magnetic Resonance Imaging in Patients Recently Recovered from Coronavirus Disease 2019 (COVID-19). JAMA Cardiol. (2020) doi:10.1001/jamacardio.2020.3557. Sartoretti, E., Sartoretti, T., Imoberdorf, R., Dracklé, J. & Sartoretti-Schefer, S. Long-segment arterial cerebral vessel thrombosis after mild covid-19. BMJ Case Reports vol. 13 236571 (2020). Coverscan - https://www.medrxiv.org/content/10.1101/2020.10.14.20212555v1.full.pdf
Association of British Neurologists	Guideline	Research Other Rec 3	We still don't really know what 'Long Covid' is . there may be two major groups presenting to neurology which have definable mechanisms and I think will fall out of subsequent research; they are not all 'the same' as manifestations are variable but the underlying pathogenesis of each group is likely to be the same. Broadly there is a 'head injury/concussion' phenotype and a post- inflammatory CNS disease phenotype with hard signs. There will always be a third group that is present for all categories of disease. And then there are the post-acute illness morbidities that are as a result of the

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			strokes/ITU/organ damage from the acute disease that are as prolonged as the systemic illness takes to get better. I do not think there are any peripheral neuromuscular long COVID conditions (at least not that I have come across so far).
Advisory Committee on Antimicrobial Prescribing, Resistance and Healthcare Associated Infection (APRHAI)	Guideline	Research Other Rec 3	The effect of vitamin D levels on recovery should be included as a research recommendation.
Faculty of Health Sciences, Oxford Brookes University	Guideline	Research Other Rec 4	All of these recommendations suffer the same fundamental weakness, namely the lack of any appropriate definition of what constitutes the syndrome. Until this is developed, and it will take a year or two to develop it at a minimum, the other projects become pointless.
Insight IAPT	Guideline	Research Other Rec 4	Validated outcome tools for primary care IAPT services for screening for psychological issues associated with their physical health include: PHQ9 - Depression GAD7/ADSM - anxiety IES -impact of event scale (PTSD) work based tool such as the WSAS to look at how psychological distress impacts on daily functioning all of the above have been clinically validated as part of the IAPT programme and are widely used within primary care and can be found in the IAPT manual which can be found here: https://www.england.nhs.uk/wp-content/uploads/2020/05/iapt-manual-v4.pdf
British Society of Rehabilitation Medicine (BSRM)	Guideline	Research Other Rec 4	Screening tools while in acute care should be included, to establish whether we can better identify patients at risk One of the developers of the Yorkshire screening tool is involved in this response. C19-YRS (Yorkshire Rehabilitation Screen) is a validated tool. It was developed by a multidisciplinary team of professionals involved in managing these patients using a consensus method. Changes were made to the questionnaire using iterative process based on feedback received from patients. The tool was used in the Leeds COVID-19 follow-up study (Halpin et al 2020) and it captured the common persistent

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			symptoms. This is supportive of its content validity to be used as a telephone screening tool for patients discharged from hospital. The tool however needs further testing for community patients (who were not hospitalised) and a self-report version needs to be developed.
Patient Safety Learning	Guideline	Research Other Rec 4	This is not a research issue. Must be informed by research, clearly, but this is a service that must be commissioned. We believe that the guidance should specify by whom and to what standard.
ME Action UK	Guideline	Research Other Rec 4	Add: Develop tools to identify whether people experiencing post-exertional symptom exacerbation after COVID-19 meet criteria for ME/CFS and propose how this can be incorporated into screening.
University College London Hospital	Guideline	Research Other Rec 4	To validate autonomic screening tool (diagnostic and patients outcome measures) to facilitate screening for autonomic dysfunction and monitoring response to treatment at primary and secondary care
West Yorkshire and Harrogate Health and Care Partnership	Guideline	Research Other Rec 4	Tools need to validated with people from different ethnic backgrounds
British Psychological Society	Guideline	Research Other Rec 4	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.
Clinical Advisors to the Scottish Government (Clinical Guidance Cell, Professional	Guideline	Research Other Rec 4	Need to be developed underpinned by more research. Greenhalgh A and Kamal suggest attempts at a range of symptomology but again needs more research.

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Advisory Group)			
Royal College of Speech and Language Therapists (RCSLT)	Guideline	Research Other Rec 4	As we mentioned in an earlier comment, we suggest piloting the Intensive Care Society Rehabilitation PICUPS tool in long covid for screening of rehabilitation needs rather than reinventing the wheel. The PICUPS screening tool encompasses the whole Multidisciplinary team approach to rehabilitation and is newly developed in response to COVID-19 by the rehabilitation collaborative - please refer to this tool.
National Institute for Health Research, Centre for Engagement and Dissemination	Guideline	Rationale	The rationale for not using the term Long Covid makes inaccurate reference to the NIHR Themed Review. The review is deliberately called 'Living with Covid19' NOT Long Covid and discusses that a number of different syndromes may be experienced after an initial Covid19 infection. It does not subdivide Long Covid into four syndromes, it recognises existing syndromes and suggests a novel syndrome may be present. The precise wording used in the review is - " 'Long Covid' is a term widely used on social media but is not a well-defined term and not a diagnosis used widely by clinical staff. The lack of empirical diagnostic tests may mean that a number of different conditions may be falling under a single umbrella term. It was noted that some people have drawn parallels with post-viral syndrome, although the general view of the group was that it is too early to conclude that the experience of living with Covid19 is always post-viral syndrome. Indeed there is a possibility that the symptoms described may be due to a number of different syndromes (e.g. Post Intensive Care syndrome, Post Viral Fatigue syndrome and Long Term Covid syndrome). Some people may be suffering with more than one syndrome at the same time'. We are disappointed that a misrepresentation of our review is being cited as a reason not to use the term Long Covid, the prefered term of those with lived experience.
Faculty of Health Sciences, Oxford Brookes University	Guideline	Rationale	There is a fundamental, philosophical difficulty that has not been discussed. In essence, a syndrome is a shorthand name for a collection of symptoms and is used when there is no better information to define the cause or causes. Most syndromes are multifactorial in cause, arise over time and do not have any obvious stages. Terminology should start from the premise that, until proven otherwise, there are no stages and boundaries are lax other than a presumed requirement that a person has had, or thinks that they have had Covid 19 infection. Given that the infection is known to be asymptomatic at times, it is going to make it very difficult to develop a usable definition. Similar problems exist for other conditions such as head injury where a large number of people believe they have problems secondary to head injury, and yet some of them have not had trauma to the head let alone sufficient trauma to injure the head and brain. It seems futile to divide the symptomatology over time for two reasons.

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			There is no biological or other reason to set any particular time limit where a boundary is crossed. Furthermore, it is unlikely that there is any such boundary, because the time course of change and recovery after the acute infection varies from person to person for reasons that are not known. It is better to recognise this reality than it is to attempt to impose time boundaries which, as this guideline demonstrates, are not really sensible.
Carers Scotland	Guideline	Rationale	Page 17, lines 18-20 As noted earlier, question whether there has been consideration of the needs of those who lack capacity and the involvement of unpaid carers and/or guardians/power of attorneys
UK Doctors Long COVID Group	Guideline	Rationale	o Page 15 Line 14-26 ‘post’ in this context is a time specific word. o Page 16 Line 17 The Yorkshire tool is based on activities of daily living after ICU and so is not relevant to most people with long COVID. It would also miss a significant proportion of the physical problems related to specific organ damage in people with long COVID, eg. Chest pain. o Page 18 line 24/5. Anxiety and depression - there is no evidence that there are higher rates in those with long COVID as explained in earlier comments. Expert testimonials should not be used as evidence in this context. o Page 19 line 8 states ‘not enough evidence to recommend specific criteria for referral’. ? Given the emerging picture of organ damage and ongoing inflammatory reactions, specific referral criteria should be developed for each body system affected, and there should be a low threshold for referral. These criteria for referral should be made a priority otherwise there is high risk of physical pathology being missed. o Page 20 line 7 We note the rehab faculty's comment in the first set of stakeholder feedback stating that they ‘hoped people would have a psychiatric assessment before being referred to rehabilitation’. This is potentially discriminating and suggests if you have a psychiatric disorder you don’t merit support for the physical effects of long COVID. ? While addressing psychological aspects of chronic ill health is important, this should be seen as a part of the recovery process not the first point of contact or assessment. ? In the event of a secondary mental health problem being identified, the patient’s physical symptoms should not be dismissed or in any way diminished by this diagnosis
Royal College of Physicians and Surgeons of Glasgow	Guideline	Rationale	The College welcomes this guideline on the management of long-terms effects of COVID- 19 which it believes is relevant and opportune. However. it recognises that this is a rapidly changing field and that this guidance may need to change equally rapidly as we learn from this new disease. It also relevant not to exclude other long-term diseases from consideration as a consequence of or part of the long COVID spectrum. The original Scope for instance excluded the symptom complexes of chronic fatigue syndrome, chronic pain syndromes and fibromyalgia. It is also possible that other symptoms may need to be added. Definitions in terms of state of the disease may need to be reviewed more frequently than usual. (P2 L12-23)

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Royal College of General Practice England, Wales, Scotland and Ireland	Guideline	Rationale	Page 15, line 13 The use of abbreviations that are not identified elsewhere in the text may be confusing. Rather than writing PCS we recommend the full terms are used i.e "ongoing symptomatic (4-12 weeks) and Post Covid Syndrome PCS (12 weeks and longer)."
The Royal College of Obstetricians & Gynaecologists	Guideline	Rationale	Page 5, line 13. Line 13. Has the abbreviation PCS been provided anywhere else in the guideline?
Patient-Led Research for COVID-19	Guideline	Rationale	In line 19 on page 16, we encourage the panel to consider questionnaires as being required to be developed in partnership with patients. We agree with line 22 on page 17 stating that there are too many uncertainties to provide definitive risk factors, and again caution against including Paragraph 2.7 in the guidelines. For line 6 on page 18, please refer to our comment on Paragraph 3.4 for our concerns on the inclusion of exercise tests in this guidance. For page 18 starting at line 28 until page 19 at line 3, we are supportive of the panel's clarity that access to services should not be restricted by the need for a positive SARS-CoV-2 test. However, we want to draw attention to the panel that it is not only a lack of testing that could be an issue, but many people with Long COVID tested negative for PCR and antibody despite having the symptoms of an acute COVID-19 infection. The PCR, antigen, and antibody tests are unreliable and cannot be a definitive marker of a COVID-19 infection.
British Geriatric Society	Guideline	Rationale	Page 15, line 21-24 Long covid is so much simpler for patients to understand that I think it will take some time for the change in names to stick, though I fully appreciate the reasoning behind them. Page 16, line 20-23 It is likely to be very difficult for GPs to know when or whether to refer older people with frailty to the covid MDTs, notwithstanding the difficulties identifying patients who had atypical symptoms, not tested acutely and in whom covid is not suspected. This situation is unlikely to resolve until there is improved recognition amongst clinicians and the public about possible covid with atypical symptoms or if a test becomes available in the community to reliably identify past infection. It is possible that this is less likely to be an issue for robust older people or those with mild frailty, who may be more likely to be able to recognise an abrupt onset of symptoms and may have more access to

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			digital technology. Many older people have comfortably embraced new technology. Until further evidence is available, it is not clear what benefit the specialised covid MDT would have for older people if there is a local frailty assessment service which provides a similar MDT approach and carries out a Comprehensive Geriatric Assessment (CGA). The CGA sounds very similar to the multipronged holistic approach anticipated by specialist covid MDTs, mentioned in section 5.6. If such a frailty service is not available, the covid MDT would need to consider the points I suggested in my comments on section 8.1, which would be covered in a CGA. Page 16, line 27 Using the term "screening" implies false positive and false negative diagnoses; how will the false positive patients be identified, or is the term screening incorrect in view of the acceptance of all patients whether covid test is positive or not? This is another cause for concern if older patients with multiple comorbidities and polypharmacy are referred to the covid MDT without having been able to fully discount other causes for their symptoms before referral is made, in case an alternative reversible cause is missed. It is not clear whether the responsibility for an incorrect diagnosis would rest with the referring GP or the lead clinician of the covid MDT? Would referring patients to a geriatrician or a frailty hub be more appropriate?
Oxford University Hospitals NHSFT	Guideline	Rationale	line 25 - poor terminology 'mental health symptoms....referred for support'. It would be better to say when depression or anxiety present refer for treatment.
Patient Safety Learning	Guideline	Rationale	Recommendations 1.1 to 1.8 – the guidance states that ‘If used, questionnaires should ideally be developed in partnership with patients and be validated’. Who will these be developed by? We would ask whether it may be best to commission these by NHSEI to prevent a piecemeal approach to this development? Or at the very least a coordination to ensure that questionnaires are validated and shared for consistent adoption. Recommendations 3.1 to 3.9 - We welcome that access to advice and support is not restricted to those that have been tested or those that have tested positive Recommendations 4.1 o 4.3 - This is urgently needed. What is the interim advice to clinicians and people living with Long COVID to ensure equitable and consistent advice and access to support? Recommendations 5.1 to 5.8 - What should self-management look like? What are the options that clinicians should consider in providing advice to people living with Long COVID? Is there a model/template rehab plan for clinicians to refer to for guidance? The guidance refers to patient organisations and support groups that can help to support self-management but does not indicate who it is referring to specifically. We are concerned the guidance in this area does not provide assurance to

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			people living with Long COVID that their clinicians know what to do and enable a consistent and equitable access to services.
Public Health Scotland	Guideline	Rationale	There needs to be a succinct review of the literature included, e.g. a table listing all reported acute symptoms and those reported as 'post covid' – as well as review of the management plans and outcomes that have been reported.
The Society and College of Radiographers	Guideline	Rationale	P19 line 18 Can the rapid guidance please reference that evidence. Overall, the recommendations are clear and take into account a person-centred approach. It will be useful to provide a description of the facilitators and barriers to the implementation of recommendations.
UK Faculty of Public Health	Guideline	Rationale	Page 15 line 13. Possibly write out PCS in full? Page 16 line 13 – screening tools - comments as above
ME Action UK	Guideline	Rationale	On page 16 line 2 you state that "Good information is needed after acute COVID-19 so that people know what to expect after their illness, including when to ask for more medical advice." However, the omission of any mention of the possibility that the patients may be at risk of or have ME/CFS, and the risks of exercise programmes for these patients throughout this document quite clearly goes against your own position on 'good information', and potentially puts large numbers of people at risk of harm. This omission should be rectified in the final document. On page 18 line 22 the rationale states that "Evidence suggested that many people struggle to adjust to changes in their life, abilities and self-identity and reported feelings of helplessness and isolation. This was also supported by expert testimony which suggested symptoms of low mood and anxiety are common". Throughout this document, there is almost no recognition that low mood and anxiety might be natural responses to the loss and suffering the patient is experiencing, similar to the grief experienced on losing a loved one, rather than a psychiatric disorder. We want patients to receive the support they need, including access to mental health professionals, but there must be recognition that many of these feelings are normal responses and that pathologising them is unfounded. Finally on page 19 line 25 it is stated: "There was very little evidence on interventions…" and "There was a lack of COVID-19-specific evidence on managing many of the common symptoms related to COVID-19, such as fatigue, dizziness and cognitive problems (brain fog)". Nevertheless, " the panel agreed that support, such as setting achievable goals, should be tailored to the person's needs". If there is little evidence, we cannot see why the committee agreed to recommend goal setting. This is putting the unsubstantiated view of a few professionals above an evidence-based approach.

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Scottish Intercollegiate Guidelines Network (SIGN) Council	Guideline	Rationale	page 18 What about echocardiography? Some evidence of COVID-related myocarditis, and the possibility of LV dysfunction and arrhythmias (eg atrial fibrillation) related to infection should not be ignored. Obviously should these complications occur, specific management should be implemented
Clinical Advisors to the Scottish Government (Clinical Guidance Cell, Professional Advisory Group)	Guideline	Rationale	The advice needs to be evidence based and although this is mentioned in the comments here and I understand the difficulties it needs to be clear what the level of evidence for statements are. It is not clear who the guideline is directed at. There is no reference to what experts were involved in which sections of development.
Long Covid Support Group	Guideline	Rationale	Page 14, lines 22-23: ‘The significant progress made by patient groups using the term ‘long COVID’ was recognised and incorporated into the definition’ feels patronising and tokenistic. Why not call it Long Covid, and include ‘post-Covid syndrome’ in inverted commas as a nod to those who prefer that term? Page 15, line 1: The NIHR Themed review cited did not refer to 4 syndromes: ‘there is a possibility that the symptoms described may be due to a number of different syndromes (e.g. Post-Intensive Care syndrome, Post-Viral Fatigue syndrome and Long-Term Covid syndrome). Some people may be suffering with more than one syndrome at the same time.’ https://evidence.nihr.ac.uk/themedreview/living-with-covid19/ Page 15, lines 4-5: Post-Covid-19 syndrome has been used in multiple ways in the literature and media. This, in itself, is not a reasonable rationale for accepting or rejecting a name. Page 15, lines 5-7: Disagree that using the term Long Covid [please use capital L] ‘alone for the basis of the clinical guideline may have confusing consequences for patient and clinicians alike’ and that Long COVID ‘as a standalone term has already been used in multiple different ways across the literature’. Page 15, line 9: What are the specific clinical criteria for Post-Covid-19 Syndrome and where is the evidence based rationale? Page 15, line 11: Codes can be developed for whatever we define. Justifying calling a disease by a particular name because of the need for codes is the tail wagging the dog. What’s wrong with Acute Covid (0-4 weeks), Long Covid (5-12 weeks) and Long Covid (>12 weeks)? Page 15, lines 12-13: We dispute the premise

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			that the condition divides into three phases (0-4 weeks, 4-12 weeks and 12+ weeks). This appears to imply a linear progression whereby the most severe symptoms are experienced in the acute phase, then gradually tail off. This does not align with the experience of many of the 31,000 members of our Long Covid Support Group: symptoms and signs experienced in the early weeks following infection with SARS-CoV-2 can persist, evolve and/or new ones develop (even after 12 weeks), a relapsing and remitting pattern is common, and symptoms can be more pronounced several weeks or months after infection than they were in the early weeks. We understand the rationale for making reference to two phases to make the distinction between people whose symptoms persist versus those who recover more rapidly, but the guideline should make clear that there may be no difference between symptoms and signs experienced in the acute stage and those experienced weeks or months later. A third, middle phase (4-12 weeks) assumes some physiological transition from one phase to another that neither reflects patient experience nor has any underpinning evidence. Page 15, line 13: We reject unequivocally the term 'Post-Covid-19 Syndrome'. The Long Covid term, originally developed by Dr Elisa Perego, an Italian academic with the condition, is well established in the U.K. and internationally, and reflects the only certainty about the condition, i.e. that symptoms can endure. In contrast to 'Post-Covid-19 Syndrome', Long Covid is an open term that makes no assumptions as to the persistence of the virus. The rationale given for creating a new term 'Post-Covid-19 Syndrome' is contradictory and flawed, since it can be argued that 'post' is also a time-specific term. The name Long Covid has the advantage that it will not become obsolete as new research findings emerge. Using Post-Covid-19 syndrome risks making the guideline out of date very rapidly. Using Post-Covid-19 syndrome also risks alienating the large and growing international community of people with Long Covid. The imposition by the medical establishment of an unwanted name, that contradicts the lived experience of patients, flies in the face of the principle in the NHS England constitution that 'patients will be at the heart of everything the NHS does'. The distinction between 'Ongoing symptomatic COVID-19 (Long Covid 4 to 12 weeks)' and 'Post-COVID-19 syndrome (Long Covid 12 weeks or more)' is unclear, especially when 'Post-COVID-19 syndrome may be considered before 12 weeks while the possibility of an alternative underlying disease is also being assessed'. What does this mean? And why the 12 week cut off point? This is an arbitrary cut off as new pathologies can arise before or after this time. If the patient has not managed to access assessment before 12 weeks will they automatically get the 'diagnosis' of post Covid syndrome? What assessment is necessary at that point if they have not had it before this? Page 15, lines 14-26: 'Ongoing' or 'post' are no less time specific than 'chronic' or 'persistent', which were rejected on this basis. The title of the document refers to 'long-term'. Post-Covid-19 syndrome (12

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			weeks) and ongoing symptomatic Covid (4-12 weeks) 'diagnoses' are time based, so this argument does not hold up. Long Covid implies no particular timeframe. Page 15, line 19: Reference to the acute stage of the illness ending makes assumptions about the natural history of the condition that have not yet been confirmed by research. If the guideline argues that use of 'the term post recognised that the acute phase of the illness has ended', it could be interpreted that up until 12 weeks a patient is still in the 'acute' phase. Also if it is 'not possible to determine how long the ongoing effects will last' (page 15 line 16), how is it possible to justify a time restricted ongoing symptomatic phase? There is evidence of persistent infection or acute disease after 12 weeks. These studies evidence persistent infection 1,2 and ongoing pathology 3–6 in patients beyond 3 months which contradicts the premise for the term 'post acute'. The term post acute has no logic given the aforementioned literature 1. Gaebler, C. et al. Evolution of Antibody Immunity to SARS-CoV-2 1 2. bioRxiv 2020.11.03.367391 (2020) doi:10.1101/2020.11.03.367391. 2. Dias De Melo, G. et al. COVID-19-associated olfactory dysfunction reveals SARS-CoV-2 neuroinvasion 2 and persistence in the olfactory system 3 4 Short title: SARS-CoV-2 neuroinvasion and persistence 5 6. bioRxiv 2020.11.18.388819 (2020) doi:10.1101/2020.11.18.388819. 3. Dennis, A., Mbbch, J. A., Badley, A. D., Anton, G. & Mbbch, D. Multi-organ impairment in low-risk individuals with long COVID. Barts Heal. NHS Trust 2020.10.14.20212555 (2020) doi:10.1101/2020.10.14.20212555. 4. Carfì, A., Bernabei, R. & Landi, F. Persistent symptoms in patients after acute COVID-19. JAMA - Journal of the American Medical Association vol. 324 603–605 (2020). 5. Puntmann, V. O. et al. Outcomes of Cardiovascular Magnetic Resonance Imaging in Patients Recently Recovered from Coronavirus Disease 2019 (COVID-19). JAMA Cardiol. (2020) doi:10.1001/jamacardio.2020.3557. 6. Sartoretti, E., Sartoretti, T., Imoberdorf, R., Dracklé, J. & Sartoretti-Schefer, S. Long-segment arterial cerebral vessel thrombosis after mild covid-19. BMJ Case Reports vol. 13 236571 (2020). Page 15, line 26: Considered the appropriate choice by who? If your choice is wholeheartedly rejected by the wider community of people with Long Covid, then in what sense is it the appropriate choice? Page 16, line 2: Why only 'after acute COVID-19'? Replace with 'after infection with SARS-CoV-2'? Page 16, line 3: Replace 'after' with 'during'. Page 16, line 12: Remove mention of phone or video appointments to allow the practitioner and patient to agree the best way, which could include face-to-face. Page 16, line 17: Yorkshire tool is based on activities of daily living after ICU. Not relevant to most people with Long Covid symptoms as there is no assessment of organ damage. Page 16, line 19: Remove the word 'ideally'. Page 16, lines 20-22: Rephrase to remove reference to age groups: The panel highlighted that some people may report different symptoms to those most commonly reported.' Page 16, lines 23-28:Why should someone with

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			Long Covid symptoms serious enough for them to seek medical attention be treated differently to anyone else in their ability to access face-to-face appointments? The recommendation for an initial screening consultation feels discriminatory. Page 17, lines 11-17: Make clear that longer appointment times may be required to allow discussion of complex symptoms and their progression. Page 17, line 19: Remove ‘, particularly older people’. Page 18, lines 22-27: There also seems to be a physiological basis to some mental health symptoms, for example many people with Long Covid report that their adrenal system/sympathetic nervous system seems to be activated on a prolonged basis. This can cause insomnia, cognitive impairment as well as feelings of anxiety. Also, there is no evidence of higher rates of anxiety and depression among people with Long Covid than in the general population. Page 19, line 8: Disagree with the statement, ‘not enough evidence to recommend specific criteria for referral.’ This statement is not true or safe, given the emerging picture of organ damage and ongoing inflammatory reactions. Specific referral criteria could be drawn for each body system affected, and there should be a low threshold for referral in the context of a new virus. These criteria for referral should be made as a priority: otherwise there is high risk of physical pathology being missed. P20, lines 2 & 11: Replace ‘brain fog’ with ‘cognitive impairment’ (which can include difficulty in concentrating and/or retaining information, problems with finding the correct words and/or spelling, and sensory overload). P20, line 3: Using language such as ‘goals’ risks people pushing themselves (potentially triggering worsening of symptoms) and also feeling a failure if goals are not achieved. Page 20, lines 10-13: What is ‘the evidence’? This list should include chest pain, muscle and/or joint pain, insomnia, exercise intolerance, menstrual changes.
NHS England and Improvement	Guideline	Rationale	Page 16, line 14 - consistency error. the expert panel are described here as 'the committee'. Page 16, line 18 - either reference this screening tool or provide a link. It is presented in the appendix of the NHSE/I 'National Guidance for post-COVID syndrome assessment clinics' and is unlikely to be identifiable especially if 'NHSE/I' is amended on publication of this guideline.
Association of British Neurologists	Guideline	Rationale	'What IS post-COVID syndrome (what are they?)' is added, followed by 'How frequent is it and what are the resource requirements'.....followed by the other questions.
Chronic Long Covid	Guideline	Rationale	Post Covid Syndrome is the correct medical term since the biomarkers for long covid have been found and it shows as a post viral illness. The 'post' term refers to after the initial infection, hence, post covid, Since we are no longer infectious this is correct. Furthermore, has been recognised for some time in the US (since June) and is used in various countries medical papers, labs, institutes etc. Some have commented on how 'long covid' is the 'patient preferred' term, however, patients in many groups have

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			not been consulted since a few are only represented. No one asked our group either. This is a medical term and we are pleased to see NICE uphold its reputation as an Institute of Clinical Excellence, since when do patient groups name an illness? Glad we are back to medical terminology. Moreover, patients are uk -wide and not in all one group so such statements are not correct that 'all patients prefer it'. Therefore, it is correct that it is a 'colloquial' term used by 'some' patients,not the majority or all of the UK patients. When this was recently put out on social media by some groups, many patients across different post viral groups commented: "We don't have 'long me' do we?", another HIV patient wrote 'how offensive is it that I might have long hiv?" and another long covid, how long is long, does that mean I am sick forever? (one of three examples written by patients from other groups, not us). Furthermore, the use of the term 'Long' or 'ongoing' or 'chronic' could equally cause confusion to patients (it causes many of us already to have to explain that we are not infectious-there is too much similarity & proximity with the image of 'covid infection' in a pandemic that frighten) as well as offence and upset (what does long here imply...a few weeks, a few months, a few years or a lifetime or permanence? As NICE have highlighted we do not yet know the longevity of the illness. The term 'long covid' has served its purpose well and we even changed our name to accommodate the 4 types being recognised (now 3) including chronic long covid. Not all patient groups thought it appropriate for a post viral illness but as a stop gap until we know more. That time has come. Perhaps down the line it may change again when the causes are unmasked and revealed. What we do know however, it is a post viral illness, so until the cause is unmasked we welcome the term, as do some other groups who posted on social media, Post Covid Syndrome.
Engender	Guideline	EIA	When we evaluate an EQIA we look at whether it: 1. Has used relevant gender-sensitive qualitative and quantitative evidence; 2. Has filled evidence gaps where needed; 3. Has applied the evidence to identify where gendered discrimination against women could be reduced and where women's equality with men can be advanced; and 4. Has used this analysis to inform the policy development by making appropriate changes to the original policy solutions or ensuring that the detailed policy development addresses the inequalities and opportunities for equality that have been identified The EQIA produced for this work meets none of these considerations in terms of Sex. In fact, it suggests that little consideration was paid to sex at all in the drafting process for any of the three limbs of the General Duty in the Public Sector Equality Duty. There are additional process concerns - its is not good practice to mix protected characteristic and other groups as EQIA is a distinct legal requirement for protected groups in the Equality Act. Adding characteristic, especially where basics relating to the legally mandated groups is so lacking, leads in our view to a weakening of necessary focus. EQIA should

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			highlight available evidence and identify gaps in evidence. In terms of Covid-19 there will clearly be significant gaps and the EQIA should make plans to address them where possible by looking at alternative evidence such as that from other countries or qualitative evidence. This EQIA does the opposite, and excludes emerging or raised trends entirely, exacerbating the information gaps and leaving critical awareness out of the early policy design. This is likely to have long-running consequences when evidence does emerge as it is very difficult to retrofit women and gender-considerations into policy and practice once up and running. The dismissal of women's experience is additionally concerning as it is a known and well-evidence gendered barrier to care. In this instance, the EQIA not only fails to acknowledge the evidence around women's dismissal but actively perpetuates it. Elsewhere emergence or assumptions are proactively considered in favour of men, for example the EQIA suggests that men may display different help-seeking behaviors. This imbalance is extremely problematic and undermines confidence in the guidance as a whole, which is currently entirely gender blind. Clinical and healthcare biases actively harm women, and there is significant body of research from around the world available which the EQIA could and should have drawn on. The evidence tables attached do indicate an extremely limited number of studies checked for sex difference, but there were a few instances included. None were mentioned. Emerging data on sex and gender difference in covid will likely have impacts for other groups including age (older women seem to be reporting symptoms in higher numbers) and transgender persons who have undertaking some form of medical gender reassignment. Gathering and using sex-difference data is a critical action that the EQIA should include as a change to the policy. Additionally, there is a wealth of data and evidence about gender barriers to services that the EQIA should draw on in terms of service design, many of which are included in specific comments but include poverty, work, provision of care, transport uses etc. Even if not distinct to Covid-19, the patterns are useful in developing clinic structures and multidisciplinary teams. As it stands, the lack of evidence in the EQIA means that there was nothing to draw on in designing the guidance. This is fundamentally incompatible with the mainstreaming purpose of EQIA, and means that women's lives and needs are entirely missing in the design of critical and life-altering services. This risks embedding further inequality and therefore the EQIA cannot conclude that there are no impacts -positive or negative - of the policy for the protected characteristic of sex.
Forth Valley Patient Public Partnership	Guideline	EIA	P2endorse comments on range of disabilities Think more issues may emerge as time goes on

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Carers Scotland	Guideline	EIA	I would like to make a general comment on the EIA. Whilst caring is not a protected characteristic, carers are covered within the Equality Act in relation to their association with a disabled person. With the recognised difficulties older and disabled people may have, where organisations have not made (or made sufficiently public) the arrangements for involvement of carers in supporting an individual with healthcare, the difficulties a disabled or older person faces may be further exacerbated.
Royal College of Physicians and Surgeons of Glasgow	Guideline	EIA	Page 3 Other definable characteristics. These need to include those in custody such as prison or long-term hospital care (eg Broadmoor, Moss-side or State Hospital, Carstairs. Homeless people are also more likely to be lost in follow up.
The Poverty Alliance	Guideline	EIA	It may be useful to outline the importance of considering equalities characteristics intersectionally as well as separately in terms of additional barriers or inequalities this may present.
Chartered Society of Physiotherapy	Guideline	EIA	The structure and format of this document is very confusing. Sections 1 and 2: page 5 Disability suggest people with learning disabilities should be added Page 6 Others identified suggest people at risk of physical and/or mental abuse should be added. Section 3.1 The potential equality issues are addressed in the guidance somewhat randomly in different recommendations, feel that there could be more consistency. Page 9 Sex: states the evidence for women being more likely to report ongoing symptoms is from social media and small sample size. Sudre, Carole H., Murray, Benjamin, Varsavsky, Thomas et al. (2020) Attributes and predictors of Long-COVID: analysis of COVID cases and their symptoms collected by the Covid Symptoms Study App. medRxiv: 2020101920214494 https://www.medrxiv.org/content/10.1101/2020.10.19.20214494v1 This study included as evidence is an analysis of data from 4182 incident cases of COVID-19 who logged symptoms in the COVID symptom study app.
Royal College of General Practice England, Wales, Scotland and Ireland	Guideline	EIA	We are very concerned at the use of the terms “Gypsies and Travellers”. This must be corrected to the appropriate term of “members of the travelling community”
Long Covid Wales	Guideline	EIA	Age – page 2, and Sex – page 3: The issue of age-related stoicism should be taken into account. Those in older generations complain less and put up with more. As they tend to have less access to

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			media, and digital media in particular, they are more likely simply to be less aware that their symptoms may be due to Long COVID. In addition, men, especially, complain less, talk less and present less. We strongly suspect that current data on the relative prevalence of long COVID in males vs females is affected by ascertainment bias. Digital accessibility – page 4: Digital accessibility is a concern. Of course, the elderly, those from socially and socioeconomically deprived groups will have less digital accessibility. In addition, in Wales, digital accessibility, especially in some rural areas, is poor. However, even with access to digital media the very fact of having Long COVID with its associated fatigue, malaise, lethargy and brain fog, can make it extremely difficult simply to contemplate 'logging in', let alone actually doing so. We would, therefore, ask that this be addressed by e.g. home visits and 1-on-1 consultations. Persons with Long COVID, who have, by definition, already had COVID-19 are almost certainly immune. The re-infection rate, now that 60 million have had first infections, appears to be lower than 1/1,000 and probably considerably less than that.
Patient-Led Research for COVID-19	Guideline	EIA	The mobility or sensory impairments barriers that older adults may face in accessing care may be present in Long COVID patients among all age groups. These barriers should be mitigated for all age groups, while being aware of the special difficulties older people face in terms of access to care and technology. We recommend adding additional barriers to the disability section of the Equality Impact Assessment. We recommend adding that Long COVID patients may be experiencing new difficulties in ADLs and may also have new transportation barriers due to new mobility, cognitive, or sensory impairments brought on by Long COVID. This creates barriers to successful attendance of in-person appointments, particularly if the individual does not have caregiver support. Not all Long COVID patients have caregiver support, and patients may need to access medical care to be evaluated for services that would provide this. Additionally, Long COVID patients with severe symptoms may be homebound and unable to leave their home to access medical care or rehabilitation due to severe worsening of symptoms with physical or mental activity. Patient-Led Research found 89% of respondents reported worsening of symptoms with physical or mental exertion. Telehealth may not be able to fully meet these patients' needs, or other barriers to telehealth as addressed in the Equity Impact Assessment may present, in which case the healthcare provider will need to work with the patient to accommodate them. We also recommend adding an additional barrier to the disability section, addressing people with disabilities who are immunocompromised and may fear accessing care due to the risk of COVID reinfection. We have concerns about the section on Race. The document notes that poorer outcomes from COVID-19 has been linked to "a number of potential higher rates of comorbidities, such as cardiovascular disease, obesity and diabetes in some black, Asian and minority

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			ethnic populations…" These comorbidities can be due to social determinants of health and systemic racism that Black, Asian and minority populations experience (https://jamanetwork.com/journals/jamacardiology/article-abstract/2773091), whereas the document implies they are due to biological differences. We urge the committee to rewrite this section with this in mind. While emerging evidence of the higher prevalence of Long COVID in women is not a representative sample, post-viral illnesses and autoimmune diseases (https://pubmed.ncbi.nlm.nih.gov/9281381/) are more prevalent in women. The similarities between these illnesses and Long COVID must be noted while we await accurate prevalence estimates of Long COVID, and given the inherent biases that exist in medicine against women, any recommendations made must be especially aware of potential impacts to women. We recommend adding to the socioeconomic barriers section that parents with Long COVID who need to seek in-person medical care may face barriers in securing childcare for their children, while clinics limit the number of visitors due to COVID precautions. This may lead to missed appointments or inability to attend in-person appointments. We also recommend adding to the socioeconomic barriers that the financial barriers of Long COVID present a significant challenge for this population. Individuals may have difficulty accessing disability employment supports or disability benefits (PIP) in a timely manner due to a combination of systemic barriers as well as cognitive or executive function deficits from Long COVID.
British Geriatric Society	Guideline	EIA	Pages 2-4 Age, Disability, Race and Digital Accessibility It is very interesting to read the first sentence about ongoing symptoms being more likely to be reported in older people. This does not mention whether it is based on a post-hospitalised cohort of patients or those with a positive diagnosis in the community. The statement is in contrast to anecdotal discussions with GP colleagues who have said the opposite. Is it possible that the ongoing symptoms attributed to covid are the same symptoms of deconditioning experienced by older people following prolonged hospital admissions for other viral illnesses, often in addition to other complications, which has been exacerbated with physical deconditioning, cognitive impairment and the progression of frailty known to have increased during lockdown and self isolation? Some older patients living at home are likely to have found it more difficult to access face to face medical care since the dramatic shift to phone and video consulting at the start of the pandemic. There has been a marked reduction in GP home visiting unless deemed absolutely essential, in order to protect patients from risk of infection. This may have reduced the likelihood of patients contacting the doctor for apparently mild symptoms, particularly if they are worried about the risks involved with attending surgery or hospital. In my personal experience, compared with patients in their 50s and 60s, there appear to be fewer older patients with the ability to conduct video

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			consultations, either hampered by dexterity, sensory or cognitive impairments or due to not having Wifi or a device with video capability. Additionally, patients may be reliant on relatives to translate for them, or may need professional translators on the phone, necessitating longer consultations to build rapport and allow adequate time for the discussions to take place at the patient's pace. These barriers would need to be addressed when specialist MDTs are introduced to ensure older people have equal access to the full benefits of the MDT. This is especially important if there is no frailty hub or similar service locally. Page 8- Age I do not think these recommendations have given enough detail on each of the recommendations highlighted, please see my comments on each recommendation (previous). Page 10- Point 3.4 I disagree with this point and think there is inequality in access to acute covid testing for older patients living at home with atypical symptoms who are not unwell enough for admission or housebound and unable to take their own swab test. I have highlighted previously the barriers to trying to diagnose acute covid presenting atypically in older people in the community, which has the potential knock on effect of missing many patients with ongoing symptoms and post-covid syndrome who may benefit from a specialist MDT. Whether through lack of public awareness of atypical symptoms or difficulty accessing the test itself, it is still not possible for patients with atypical symptoms to request a testing kit as they do not fulfill the criteria on 111 or 119. Even if a patient manages to succeed in being sent a test, unless a family member is willing to undertake it for them, the dexterity and executive functioning necessary to correctly administer and return the test may make it very difficult for an older person with physical or mental impairments to carry it out themselves. There is still no coordinated national response to provide testing in the home for vulnerable or housebound patients with atypical symptoms or who cannot request or conduct the test themselves, unless they are ill enough to need to be admitted to hospital. This needs to be urgently rectified if we are to ensure the detection of all patients who have possible ongoing covid symptoms or post covid syndrome.
Patient Safety Learning	Guideline	EIA	There is no mention of people who identify with the Gypsy, Roma, or Traveller communities.
The Society and College of Radiographers	Guideline	EIA	The Society and College of Radiographers urge the authors to please review evidence related to gender reassignment and health outcomes, for example, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4802845/ There are a number of factors that can dissuade trans people from seeking healthcare in this context.
UK Faculty of Public Health	Guideline	EIA	Excellent coverage of the protected characteristics but we would always recommend including a recognised index of deprivation specifically as it appears in our experience to be a useful, and

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			independent, risk factor expressing a wider range of complex disadvantage that can aid public health efforts and focus at place-based level.
ME Action UK	Guideline	EIA	The possibility of inequalities in provision is considered in this section on the BAME community, under “Race”. Similarly another section of society at risk of inequality is women. Although there was some evidence that more men were badly affected by acute COVID, the evidence from previous post-viral syndromes has been that more women than men are affected. Recent studies have highlighted the risk that women’s concerns and symptoms can be belittled or ignored by the medical services. To adapt this guideline’s Equality Impact Assessment statement on “Race”, - “There is a risk that women may feel marginalised, have experienced misogyny or being patronised , or have had previous experiences with an insensitive healthcare service and that could create barriers to engagement with healthcare services.” This risk should be examined by NICE in the Equality Impact Assessment.
Royal College of Nursing	Guideline	EIA	General - May need to review the existing Equality Impact Assessment (EqIA) based on wider comments received. 3.4 - consideration should be given to providing services / information in accessible formats
West Yorkshire and Harrogate Health and Care Partnership	Guideline	EIA	Section 1.2 Race – We need to acknowledge that there is a higher level of digital exclusion among people from ethnic minority communities, and the importance of providing face to face options. Also, language may be a barrier for some patients and it is important provide alternative formats. Socioeconomic factors – Need to acknowledge higher level of digital exclusion among people living in poverty, meaning that video or telephone follow up may be challenging. Section 1.3 We need to do further work with communities with long Covid to understand needs, barriers etc. This should include communities from different backgrounds, and co-production of services. It is also important to review patient records to understand who is assessed for long Covid, needs, and what referrals are made. This requires better recording in primary care. Section 2.1 Ethnicity/race could be included here, given potentially higher rates of long COVID. Need to ensure services are accessible and appropriate. Section 3.1 There needs to be greater recognition of the different impacts on people from different ethnic and socioeconomic backgrounds. E.g. the same symptoms may have a very different impact on someone from a BAME background with a caring role, or someone who is in informal employment. We need more consideration of how to link people with with wider support for caring, benefits advice etc. Section 3.4 It may be more difficult for people from some BAME backgrounds and with limited socioeconomic resources to access services, due to digital exclusion and physical access barriers (e.g. geographical, travel cost, trust). Your COVID recovery is only available in English. Many people will need self management resources, including people with English as a second language or people who

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			need accessible information. Materials are needed in other languages, video, accessible formats. (note line numbers are not shown, so we have referenced the sections instead)
CDH UK - The Congenital Diaphragmatic Hernia Charity	Guideline	EIA	Point 1.2 Disability - I feel that there should have been a reference to vulnerable groups with conditions that have similar symptoms to Covid-19 and the challenges of recognising/separating them from each other and also how vulnerable groups within the disability setting are determined. This is also a point for further research?
Long Covid Support Group	Guideline	EIA	Page 2 - Age: Rephrase to make clear that there is insufficient robust evidence to make any of the assertions in this section. Page 2 - Disability: The guideline should make clear that many people with Long Covid have impairments (temporary or otherwise) on account of their condition (e.g. mobility, vision, cognitive impairments). Page 5, 2.1 Disability acknowledges this. People with Long Covid should be considered to have a disability within the Equality Act Page 2 - People at higher risk of COVID-19: There is insufficient information about who is at risk of Long Covid Page 3 - Race: Amend ‘key worker roles in health and social care’ to include other key worker roles that incur risk of above average exposure to the virus, for example in public transport, retail, roles for employers who may not have effective infection control measures in place. Page 3 - Sex: Include mention of the fact that there is some evidence that - among non-elderly patients - women may be more likely to be affected by Long Covid than men. https://covid.joinzoe.com/post/long-covid Page 5, 2.1 Sex acknowledges this may be an issue. Page 3- Socioeconomic factors: Include that people from certain backgrounds may be more likely to work in roles with above average risk of above average exposure to the virus - see point about race, above. And have digital accessibility issues (although this is covered in a separate point on page 4). Page 3 - Other definable characteristics: Include people in prison and others mentioned on page 6. Page 5 - Age: Replace ‘post-COVID-19 syndrome’ with Long Covid ‘Some older people may be less active on digital media (such as social media) and so may not be exposed to campaigns that raise awareness about post-COVID-19 syndrome affecting older people. As a result, older people might be at higher risk of presenting late to services.’ This sentence implies that people seek medical help only as a result of being made aware of Long Covid, rather than because of experiencing frightening and potentially serious symptoms. Page 6 - People at higher risk of COVID-19: There is insufficient information about who is at risk of Long Covid. Should this read ‘severe’ COVID-19? Page 8 - Age: ‘Recommendation 1.6 alerts clinicians to be aware that adults and children may not present with the more common symptoms associated with post-COVID-19 syndrome and that their symptoms may not be picked up by initial screening.’ - Many people of all ages do not experience the symptoms officially recognised by the NHS. ‘Recommendation 2.7 highlights the potential for older people to be more likely

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			to develop post-COVID syndrome.' - There is insufficient robust evidence to support this assertion. 'Recommendation 5.6 highlights that additional support should be considered for older people with ongoing symptoms of COVID-19, for example care packages and support with social isolation.' - People of all ages may need support with care packages and/or support with social isolation. Page 8 - Disability: The guideline should make clear that many people with Long Covid have impairments (temporary or otherwise) on account of their condition (e.g. mobility, vision, cognitive impairments). Page 5, 2.1 Disability acknowledges this. People with Long Covid should be considered to have a disability within the Equality Act. Page 9 - Pregnancy and maternity: 'Recommendation 1.4 offers people who have symptoms to be offered either a telephone or video consultation, in order to help reduce any difficulties people may have in accessing services.' People should also be offered face-to-face appointments.
Association of British Neurologists	Guideline	EIA	There is a section on particular groups (those at greatest risk for various reasons) – I wonder whether those with occupational-acquired Covid (particularly those with high exposure, some of whom have experienced Covid for a second time) should be mentioned as a group too.
Royal College of Speech and Language Therapists (RCSLT)	Guideline	EIA	Pregnancy - effect on the unborn child of maternal COVID-19 infection is currently little understood and needs monitoring. Any concerns raised by mothers should be responded to by healthcare practitioners. Age - in addition to mobility and sensory deficits mentioned, they need to include people with dementia who are vulnerable to infection, subsequent deterioration and may struggle to communicate their needs. Gender - whilst men appear to be more prone to severe illness in COVID-19, women may be disproportionately affected by long-Covid We note that speech and language therapy is noted in the EIA but this is not reflected in the Guideline
Deaf Scotland	Guideline	EIA	2. EQIA Suggest Protected Characteristics/Equality rather than just Equality Item 1.1 ……..communication, language or engagement……. Need to consider "intersectionality: people will have multiple conditions/protected characteristics. AGE Age related hearing loss/links with dementia & potential for misdiagnosis? Disability: need to re-assess accessibility? BSL language/Braille etc here? Gender Reassignment: may have issues re videolinks/sharing info? Pregnancy & maternity: nothing to add Race: Language & cultural barriers? ….others nothing to add Other Definable: Gypsy Travellers? BSL users? Rurality? Digital Accessibility There may be benefits/adaptions to some groups: visual communication, lip-reading and use of captions/subtitles/share documents and use of notetakers. item 1.3 – Very little date regarding deafness across spectrum with four key pillars: Deaf (likely to be Sign Language users?); Deafened, Deafblind (including tactile communication) & Hard of Hearing. Can this be addressed more routinely?

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National Voices	Guideline	EIA	In the given time, we are not able to collate feedback from our members, some of whom are very expert, on the content of this assessment, but it strikes us that it is likely to miss some equality perspectives as it currently stands. Largely, because people's life experiences can be very different depending on which group they fall into. Services need to be mindful of this. For example, it is well documented that men are less likely to seek support with mental health symptoms, whereas women's physical symptoms are more likely to be dismissed as 'in the mind'. Further, women often have more informal care responsibilities which can in turn impact their ability to look after their own health, particularly since the people they support (children, older relatives etc) are currently often unable to access their normal support services due to the ongoing Covid crisis. Equally, we are aware that LGBTQ+ citizens have far higher incidences of mental ill health, something that surely needs to be reflected in any service model. These are just two examples. We think this assessment would benefit from the expert input from equalities charities, and as such recommend engagement with the Health and Wellbeing Alliance, which could offer deep insight or engage in specific work around long Covid.
POTS UK	Guideline	EIA	We are aware that as a charity we have struggled to engage and access support for people from minority ethnic groups and that this is likely to be a combination of biases in referral as well as self-referral. Considering how to ensure engagement in these communities is vey salient and important and we commend and support this initiative.

Stakeholder	Document	Section	Agree with Case Definition	Comment
NICE GP Reference Panel	Guideline	Case Definition	Yes	as most are recovered without persistent symptoms 12 weeks seems reasonable. need to exclude long term consequences of eg PEs, post ITU effects.
National Institute for Health Research, Centre for Engagement	Guideline	Case Definition	No	Using a temporal scale with linear journey from acute to ongoing to 'post' suggest a degree of certainty about the aetiology. Some people report the acuity is more severe after 4 weeks, following an initial mild presentation

Stakeholder	Document	Section	Agree with Case Definition	Comment
and Dissemination				
NICE GP Reference Panel	Guideline	Case Definition	Yes	Reasonable to wait 12 weeks to see if symptoms settle before labelling the patient with post covid syndrome
Engender	Guideline	Case Definition	Yes	
Royal College of Occupational Therapists	Guideline	Case Definition	Yes	
NICE GP Reference Panel	Guideline	Case Definition	Yes	Clear boundary based on timing rather than symptom severity, which is subjective. Post implies that the acute phase is over, which helps people understand the issue.
Forth Valley Patient Public Partnership	Guideline	Case Definition	Yes	I am impressed by the speed and depth of the scope of the guideline and feel it will be an essential tool in what is to some extent an emerging area of concern during the Pandemic and thereafter As a lay person feel bases are all covered but fear the following of its recommendations may throw up some demanding areas for partnership working Particularly commend its emphasis on Self Management and meaningful involvement of patients,families and carers in dialogue on decisions
NICE GP Reference Panel	Guideline	Case Definition	Yes	
Lifestyle, Exercise and Nutrition Improvement (LENI) Research Group	Guideline	Case Definition	Yes	These are agreed by both scientific and patient groups and there is no reason to be changed.
Faculty of Occupational Medicine	Guideline	Case Definition	Yes	

Stakeholder	Document	Section	Agree with Case Definition	Comment
Faculty of Health Sciences, Oxford Brookes University	Guideline	Case Definition	No	"I do not think that the definitions are clinically plausible or useful, nor do I think they are useful in terms of research or giving guidance. The first fact that has to be recognised is that a significant proportion of people are infected but develop no symptoms. The precise proportion is not yet known. However, particularly with the advent of mass testing, a large number of people are going to know that they have had an infection even if they had no symptoms, and at the same time large number of people are going to think that they have had the infection and attribute later symptoms to it. In none of these cases can any cause or effect be proven or demonstrated. Consequently there is no plausible way to state that two people with identical symptoms can be separated, one person who has post Covid syndrome and one person who does not have post Covid syndrome. The only differentiating factor is that one person thinks they are due to Covid, and attends a post Covid clinic whereas the other person attributes it to a slight bang on the head, and gets referred to a head injury service. The second factor that has to be recognised is that, after any infection or other acute onset illness, the time course of change and recovery varies between patients for no known reason in most cases. There is no credible biological reason for imposing time boundaries on that process of change, and it is much more appropriate to consider the patient's situation at the time in relation to their trajectory prior to presentation. For example someone presenting three weeks after a very severe infection with some symptoms is unlikely to need much if anything. In contrast, someone who has similar symptoms 15 weeks after with no signs of any improvement over the preceding 10 weeks, and possibly signs of worsening would certainly need intervention. Putting arbitrary time limits is simply a recipe for getting into a muddle, denying some patients help when they would obviously need it but, by the same token, setting up interventions for other patients when they clearly do not need it. The fundamental problem is that this is being looked at from a very strictly biomedical perspective, that there is some damage caused by a virus and that that damage is itself entirely responsible for everything that follows, and that all symptoms can be attributable to the damage caused by the virus. This is just totally implausible, and any general practitioner will recognise this."
Cardiff and Vale UHB	Guideline	Case Definition	No	PAGE 2 Line 13-14 Ongoing symptomatic COVID-19 (long COVID 4 to 12 weeks): Signs and symptoms of COVID-19 from 4 weeks up to 12 weeks. Delete the bracket, as this is not long covid at this stage (Long COVID 4-12 weeks) as this confuses, So it now should reads:

Stakeholder	Document	Section	Agree with Case Definition	Comment
				Ongoing symptomatic COVID-19: Signs and symptoms of COVID-19 from 4 weeks up to 12 weeks
NICE GP Reference Panel	Guideline	Case Definition	Yes	
Patient Advisory Group to the CFS/ME Research Collaborative (CMRC)	Guideline	Case Definition	Yes	
The ME Association	Guideline	Case Definition	No	As already stated, this guidance could learn a lot from charity and physician experience of dealing with people who have a variety of post infectious fatigue syndromes In other words >> The first definition is OK for people who remain symptomatic for up to four weeks After four weeks it would be more appropriate to be labelling this as a Long/Post COVID syndrome And where symptoms persist for more than three months, and are consistent with diagnostic criteria for ME/CFS, serious consideration should be given as to whether the person does now have Post COVID ME/CFS
Polymyalgia Rheumatica and Giant Cell Arteritis Scotland (PMR-GCA Scotland)	Guideline	Case Definition	Yes	I accept the debate that took place as described within the rationale and the decisions arising from it.
Carers Scotland	Guideline	Case Definition	Yes	
UK Doctors Long COVID Group	Guideline	Case Definition	No	o Page 2 Lines 15-21 We are concerned by the use of the term ‘Post-COVID syndrome’. We recognise your statement that this is a living guideline and will be updated as more evidence about the underlying condition becomes apparent. We suggest that the term ‘Post Acute COVID’, ‘Post Acute COVID syndrome’ or ‘Persistent COVID syndrome’ are more appropriate as they support the premise that the disease process is ongoing and that there

Stakeholder	Document	Section	Agree with Case Definition	Comment
				may be virus persistence. It is important to note though that the majority of our members prefer the term 'Long COVID'. o Page 2 Lines 12-21 The definition hinges on "signs and symptoms of COVID' without listing these. A list of or reference to the most common symptoms should be included here with the proviso that symptomatology is varied and not limited to the list. o Page 2 Lines 13-21 Post-COVID Syndrome ? There is an artificial division between 4-12 wks and 12+ wks – is this division necessary given it does not alter the recommendations for investigation/referral in the guidance? ? What level of assessment is necessary to attribute a patient to one of the terms? • If a patient has not been assessed by 12 weeks of symptoms would they automatically be diagnosed with 'Post-COVID syndrome'? ? How do you define 'alternative diagnosis' in relation to ruling out Post-COVID syndrome and excluding it as a diagnosis? • Would specific organ damage related to COVID (eg. COVID related myocarditis/COVID related myelopathy) be excluded from a diagnosis of Post-COVID syndrome? • If yes then a full assessment for potential organ pathology needs to be conducted before any patient is given the diagnosis of 'Post-COVID syndrome'
Insight IAPT	Guideline	Case Definition	Yes	So little is still known about the long-term effect of COVID-19 on people's health and well-being. A lot of the physical and psychological ongoing problems following COVID are similar to other effects from other long-term conditions so a specific way of treating the psychological distress associated with breathlessness, chronic fatigue, insomnia would be treated in the same way that we work with patients with other long-term conditions which we already have pathways to support across England (Scotland, Wales and Ireland are not part of the governments IAPT programme)
British Society for Rheumatology	Guideline	Case Definition	Yes	
Royal College of Physicians and Surgeons of Glasgow	Guideline	Case Definition	Yes	It is probably as good as it can get in the current state of knowledge The College welcomes this guideline on the management of long-term effects of COVID-19 which it believes is relevant and opportune. However. it recognises that this is a rapidly changing field and that this guidance may need to change equally rapidly as we learn from this new disease. It also relevant not to exclude other long-term diseases from consideration as a consequence of or part of the long COVID spectrum. The original Scope for instance excluded the symptom complexes of chronic fatigue syndrome, chronic pain syndromes and fibromyalgia. It is also

Stakeholder	Document	Section	Agree with Case Definition	Comment
				possible that other symptoms may need to be added. Definitions in terms of state of the disease may need to be reviewed more frequently than usual. (P2 L12-23)
The Poverty Alliance	Guideline	Case Definition	Yes	
NICE GP Reference Panel	Guideline	Case Definition	Yes	I think this is reasonable way to define the illness. There key thing is that a definition is proposed and then everyone needs to use it!
Asthma UK/British Lung Foundation	Guideline	Case Definition	No	Our understanding is that people affected by long-covid strongly prefer the term 'long covid' to 'post covid syndrome'. We believe this should be respected and the name that has the greatest recognition and support among those affected used. It is also the term that is most likely to be searched for online, so using it consistently will help people find the right information. Asthma UK and the British Lung Foundation are currently reviewing our health information to take this into account.
Chartered Society of Physiotherapy	Guideline	Case Definition	Yes	Add irrespective of whether they have had a positive SARS-Cov-2 test. There needs to be recognition of different presentations of post-COVID-19 syndrome/different syndromes. Management and recovery trajectory will depend on the severity of the acute infection, the impact of intubation/ICU, and/or organ damage. Some people will present with signs and symptoms which are slowly improving and timing of recovery correlates with the severity of the acute infection. There is also a subgroup who have had less severe acute infection but fluctuating and new symptoms after the acute infection phase, the recovery trajectory for this group is less predictable. Suggest a definition of post exertional malaise should be included
ICUsteps Peer Support Charity	Guideline	Case Definition	Yes	This seems reasonable at our present level of understanding
Royal College of General Practice England, Wales, Scotland and Ireland	Guideline	Case Definition	Yes	Overwhelmingly, from across the 4 nations of the GP community the answer to this question was yes, the terminology is accurate.. Lots of reasons were given but some are included here from our clinical adviser network include -As a scientist, I can see the logic and precision of these definitions -the inclusion of time scales in the definitions is clear and is of great help clinically. -the definitions are clear -I think this is a good framework/compromise. The time spans feel intuitively useful in terms of how to think about things. -This seems sensible and reasonable in terms of classifying covid-19 -The most practical definition so far -Yes. however suggest remove the "long covid" name in brackets as this is confusing -Seems

Stakeholder	Document	Section	Agree with Case Definition	Comment
				logical and terms need agreeing. -these descriptions accord with the observed trajectory of Covid other similar disorders such as "post viral syndrome" -It follows the conventional naming we have for all other disease. Acute/Ongoing and Post. 'long' would be a unique naming convention and won't stand the test of time and could be confusing for historic reviewing in future years. -Patients will use Long Covid but as doctors we need a scientific terminology to help us. This definition covers it well -Happy with the explanation given for choosing this nomenclature. Need to differentiate different time periods. -3 time periods are well defined. 2 GP responses did suggest using the term Long Covid in preference but this was in relation to patients choice and advocacy.
Long Covid Wales	Guideline	Case Definition	No	Creating clinical definitions for various time points during the course of this illness makes an assumption, which we do not consider to be backed up yet by the literature, that the disease process of Long COVID will progress according to a set course over time. Lessons from patient forums would rather indicate the opposite; that patients will have a highly varied course with symptoms and signs unable to be grouped into specific periods of the illness. We therefore do not recognise that Long COVID is divisible into different time frames; rather, it is a continuum from the acute infection, with a complex individual time course often including relapsing and remitting phases. Any clinical activities planned according to such phases will therefore be inaccurate. Furthermore, Long COVID not being defined until symptoms have persisted until week 12 carries significant clinical risks including delaying urgent specialist input: significant pathology can occur on both sides of this cut-off and patient management must therefore be equal throughout the course of the illness rather than risk discriminatory decisions being made based on an arbitrary time stamp. Instead, these guidelines need to emphasise that complications of Long COVID are to be expected at any time and therefore require a high clinical suspicion towards the development of any new or severe, persisting symptoms, and Long COVID-specific referral pathways need to be equally accessible regardless of time frame. It is not sufficient to say that the diagnosis may be considered before 12 weeks. We also disagree with the term 'Post COVID syndrome', for a number of reasons. The issue is eloquently discussed in a BMJ article (https://blogs.bmj.com/bmj/2020/10/01/why-we-need-to-keep-using-the-patient-made-term-long-covid/). We appreciate the authors' views that Long COVID is not suitable as various uses of the term Long COVID exists in the literature and media. However, defining this illness remains an ongoing, adaptive process with learning being had along the way. Comparably,

Stakeholder	Document	Section	Agree with Case Definition	Comment
				the current use of 'post COVID syndrome' already introduces extra unnecessary confusion and, in any event, is itself likely to change drastically with future understanding and will, therefore, by this argument become an equally unsuitable term down the line. Instead, we believe that an acceptance must be had to this being an evolving illness, and the correct definition of a consistently used term will evolve with it. We appreciate the comments regarding the word 'post' referring to it recognising the acute phase having ended. However, as previously discussed the cut-off between the acute and long-term phase is not clear cut, and acute symptoms often overlap with more longer-term ones with relapses and recurrences being common. We therefore do not believe this distinction is valid. Furthermore, as previously mentioned, that Long COVID is 'post' may be a fallacy as viral persistence (see https://www.biorxiv.org/content/10.1101/2020.11.18.388819v1 and https://www.biorxiv.org/content/10.1101/2020.11.03.367391v1) may be the explanation for the ongoing symptoms. We would also like to warn that much of what is currently known about Long COVID may well be subject to ascertainment bias. Furthermore, it would at this late stage in the process be confusing, difficult and expensive for well-established groups, such as our own, to suddenly rename our organisations, websites, social media handles and email addresses. Lastly, acknowledging the term Long COVID by applying it to these guidelines would demonstrate respect and appreciation to the fact that this is a patient-discovered and patient-identified illness. It would also show appreciation of the significant work patient groups have put into not only raising awareness about the illness, but also carrying out informal yet substantial research, which has greatly contributed to our current understanding of Long COVID. We are also very concerned that replacement of the already well-established term Long COVID could be used as a further justification to deny, obstruct and gaslight patient access to medical services.
British Society of Rehabilitation Medicine (BSRM)	Guideline	Case Definition	Yes	
The Royal College of Obstetricians & Gynaecologists	Guideline	Case Definition	Yes	

Stakeholder	Document	Section	Agree with Case Definition	Comment
UEA/Fifth Sense/The Norfolk Smell and Taste Clinic	Guideline	Case Definition	Yes	typically 12 weeks is used as a cut-off for chronic
Patient-Led Research for COVID-19	Guideline	Case Definition	No	The distinction into three acute, ongoing symptomatic, and post-COVID phases is artificial and not backed by evidence. The rationale given for these three phases was that specific clinical diagnostic criteria needed to be identified to facilitate access to support needed, provide the basis for planning appropriate services, and to enable formal codes to be developed for the purpose of clinical datasets. However, there is no evidence that concludes that support or services should be different for 4-12 weeks and 12+ weeks. Having two terms - one for the initial month of the infection and one for Long COVID - is more aligned with the patient experience and is what we recommend NICE/SIGN/RCGP use for the purpose of this guidance. We understand that Long COVID has come to mean a variety of definitions. However, NICE/SIGN/RCGP has the opportunity to standardize the definition of Long COVID in these guidelines. Long COVID is both a preferred term amongst patients, and the term most commonly used by the global emerging COVID patient advocacy movement (see Perego et al https://blogs.bmj.com/bmj/2020/10/01/why-we-need-to-keep-using-the-patient-made-term-long-covid/). Given historical biases against patients in medicine (https://bmcmedicine.biomedcentral.com/articles/10.1186/s12916-015-0437-x), it is essential that the scientific community demonstrate that they are listening to and working with patients; using a patient-preferred term is one way to do that. The term “Post-COVID-19 syndrome” is not an accurate way to define the long-term effects of COVID-19. A preprint by Dias De Melo et al (https://www.biorxiv.org/content/10.1101/2020.11.18.388819v1.full) found that three patients with prolonged (between 110-196 days) and recurrent olfactory function loss after COVID-19 had a high viral load in the olfactory mucosa, suggesting viral persistence. A second study by Gaebler et al (https://www.biorxiv.org/content/10.1101/2020.11.03.367391v1.full.pdf) found SARS-CoV-2 in the gut an average of 4 months after diagnosis. A third study by Yan et al (https://jamanetwork.com/journals/jamaophthalmology/fullarticle/2771320) found viral antigen in the eye at 2 months after diagnosis. These studies indicate that Long COVID may not be post-COVID after all. There is too little known about the cause of Long COVID to make the assumption that the symptoms are not a result of current COVID-19 infection, and implying

Stakeholder	Document	Section	Agree with Case Definition	Comment
				otherwise would create confusion in both research and treatment. A “syndrome” is a group of symptoms which consistently occur together which indicate a specific condition for which a direct cause is not necessarily understood. The Patient-Led Research team has documented 205 symptoms that Long COVID patients experience. Some patients have exclusively neurological symptoms, some experience exclusively respiratory symptoms, and some experience post-exertion malaise with no other symptoms. While there are certain symptoms that have very high prevalence, we do not yet have analysis on whether specific symptoms consistently occur together. In fact, from our personal experience as patients and being part of the Long COVID community, each Long COVID patient has a unique experience. This diversity of experience is not reflected in the definition of a syndrome. We agree with the panel that terms such as “chronic” or “persistent” should not be used since it is not possible to determine the disease length. Our recommended terminology is the following: Acute COVID-19 infection: Signs and symptoms for COVID-19 for up to 4 weeks Long COVID: Signs and symptoms that develop during or following a confirmed or suspected infection consistent with COVID-19 and which continue for more than 4 weeks. Long COVID usually presents with fluctuating and unpredictable symptoms, can affect any system in the body, and can affect multiple systems at once and over time.
British Geriatric Society	Guideline	Case Definition	No	I think the words "persistent or recurring" should be inserted before "signs and symptoms of covid". Please explain within the text of "post covid-19 syndrome" more detail about what the clusters of symptoms are.
The Royal College of Pathologists	Guideline	Case Definition	No	Unable to comment - question was not asked during comment collation
Action for M.E.	Guideline	Case Definition	No	There needs to be an acknowledgement that some people will go on to develop M.E./CFS following infection. https://pubmed.ncbi.nlm.nih.gov/26475444/ By eliminating those who fit the diagnostic criteria for M.E./CFS you remove the risk of harmful and damaging management techniques. You also allow those patients the chance to understand more about the condition they have and what they need to do to manage it.
Oxford University	Guideline	Case Definition	Yes	clinically sensible and fit with experience to date

Stakeholder	Document	Section	Agree with Case Definition	Comment
Hospitals NHS FT				
Faculty of Pain Medicine of the Royal College of Anaesthetists	Guideline	Case Definition	Yes	
Patient Safety Learning	Guideline	Case Definition	No	We would advise that the term Long COVID is used. It is confusing to have different terms throughout the documents and the best approach would be to use the term commonly accepted and used by patients.
Public Health Scotland	Guideline	Case Definition	Yes	Nationally agreed definitions need to be made and these seem appropriate.
British Society for Immunology	Guideline	Case Definition	Yes	
The Society and College of Radiographers	Guideline	Case Definition	Yes	
Science for ME	Guideline	Case Definition	No	We do not support the use of the umbrella term 'post-Covid-19 syndrome'. The approach of labelling all post-Covid-19 issues as 'post-Covid-19 syndrome' when those issues potentially include strokes, lung damage, heart damage, capillary clotting, loss of the sense of smell, post-viral syndrome/ ME/CFS, and PTSD risks specific issues being written off and remaining unaddressed. It is important to assess each individual to identify what specific problems they have and follow best-medical practice to manage each identified issue, while also considering the person as a whole.
Long Covid SOS	Guideline	Case Definition	No	Post Covid 19 Syndrome is disputed and has been overwhelmingly rejected by patients and patient groups. More evidence of persistent infection in some people with Long Covid is emerging e.g. https://www.biorxiv.org/content/10.1101/2020.11.18.388819v1.full#ref-12. We should not use the term 'post' without evidence that all sufferers are post infection - it is misleading and makes assumptions which cannot be backed up. The term "Long Covid" is now in general use by patients, members of the public, policy-makers, clinicians and researchers. Imposing a name which has been rejected by sufferers - who have been at the forefront of research and data gathering into the condition - is ill advised.

Stakeholder	Document	Section	Agree with Case Definition	Comment
BAME Health Collaborative (BHC)	Guideline	Case Definition	Yes	Yes because it is a global approach and creates a standardised terminology for all.
ME Action UK	Guideline	Case Definition	No	The name long COVID is favoured by most long COVID patient groups and so #MEAction would support this term. As people with experience of living with a trivialising disease name (chronic fatigue syndrome), and who have had to use precious energy and resources to advocate against this, we strongly urge the committee to accept patient choice in this respect. The definitions are based entirely on length of time since COVID-19 infection. Some people will have specific heart or lung problems whilst for others, post-exertional symptom exacerbation/post-exertional malaise (PESE/PEM) will be a major symptom. All diagnostic criteria developed for ME/CFS in the past decade now characterise PEM as a hallmark symptom of ME/CFS. What is the evidence to also include it as a symptom of long COVID, instead of taking it as an indication that the patient probably has coronavirus-triggered ME/CFS? We are very concerned that these different subsets of people will not get appropriate care if all are considered together in this loosely defined post-COVID-19 syndrome.
The Richmond Group of Charities	Guideline	Case Definition	No	Our members Asthma UK and the British Lung Foundation understand that people affected by ‘long-covid’ strongly prefer the term ‘long-covid’ to ‘post-covid syndrome’. We support their view that this should be respected and the name that has the greatest recognition and support among those affected used. It is also the term that is most likely to be searched for online, so using it consistently will help people find the right information. Asthma UK and the British Lung Foundation are currently reviewing their health information to take this into account.
Co Durham CCG	Guideline	Case Definition	No	The feeling locally was that given we are using a very person centred approach and wanting to support a psycho-social approach using a term which was coined by those who were experiencing this rather than a medical term. There was also concern about calling anything a ‘syndrome’. Current national terminology is a missed opportunity to promote the importance of ‘Living Well with..’ focussing on self-management of modifiable factors and other determinants of health including lifestyle and wellbeing supported by a robust psychological approach.

Stakeholder	Document	Section	Agree with Case Definition	Comment
Clinical Effectiveness Southwark	Guideline	Case Definition	Yes	
British Thoracic Society	Guideline	Case Definition	Yes	We are grateful for the opportunity to comment on this guidance which we note should be regarded as provisional and subject to evolution as more evidence becomes available. We welcome the emphasis on considering alternative 'non-COVID' pathology in symptomatic people. We also welcome firm definitions of the stages of illness and recovery.
National Kidney Federation	Guideline	Case Definition	Yes	
Chest Heart & Stroke Scotland	Guideline	Case Definition	Yes	The three areas provides clarity in terms of how we can consistently define the phase of recovery for the patient, family, and care givers.
University College London Hospital	Guideline	Case Definition	Yes	
Royal College of Nursing	Guideline	Case Definition	Yes	Seems appropriate based on current evidence
Lesley Macniven Consulting	Guideline	Case Definition	No	Prefer Long Covid as a term. Several social science papers were excluded due to ‘expert opinion’ status, when they are evidence-based and valid. This is potentially biased against input from the medical humanities, which is arguably essential in naming conditions. The rationale regarding the name does not hold water -- Long Covid is an open and polyvalent term, and this should be embraced. It is in fact 'Post Covid-19 Syndrome' that introduces a lack of clarity, as well as stigma, not to mention the fact people living with Long Covid have begged NICE not to use this term. Using this term, when stakeholders have pointed out the stigma of 'post' and 'syndrome', and when people living with Long Covid so clearly do not want it, is knowingly, and actively, contributing to the abuse of patients. LongCovidSOS make a good case here: https://www.longcovidsos.org/post/why-post-covid-19-syndrome-is-he-wrong-choice
Department of Health (Northern Ireland)	Guideline	Case Definition	Yes	

Managing the long-term effects of COVID-19
Targeted consultation on draft guideline
Comments table
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Stakeholder	Document	Section	Agree with Case Definition	Comment
West Yorkshire and Harrogate Health and Care Partnership	Guideline	Case Definition	Yes	
Public Health England	Guideline	Case Definition	No	Terminology: long COVID-19 12 weeks or more, this is a colloquial term. Post-acute COVID-19 is a more appropriate term. With regards to the time, it is difficult to come up with a cut off point for when the symptomatic illness ends versus the post-COVID-19 syndrome starting. 12 weeks is perhaps a bit too long, given that the virus is detectable for 10 days in most people and there is little in the literature to document any clear switch from ongoing post-infection symptoms such as breathlessness, chronic cough, or fatigue compared to a post-COVID-19 syndrome. In general infections we tend to say 6-8 weeks for recovery from an illness such as pneumonia, so you could use 8 weeks as an upper limit. However, we realise that none of this will be evidence-based and it may be that 12 weeks is better, to assume a degree of specificity of the terminology. It may be worth including a sentence outlining the limitations in the literature and that this time period is a practical choice.
Sheffield ME and Fibromyalgia Group	Guideline	Case Definition	No	We strongly support using terminology that is accessible to patients and supported by them. The most commonly used term is now long COVID and we feel this is much more appropriate than post COVID 19 syndrome. Defining a clinical entity based entirely on length of time rather than opening the possibility of different subsets could lead to care for patients that is not adequately tailored to symptomology.
CDH UK - The Congenital Diaphragmatic Hernia Charity	Guideline	Case Definition	No	I feel there is potential for confusion between the ongoing and post-covid descriptives. In particular the fact that post-covid syndrome may be considered before 12 weeks, which falls into the ongoing covid-19 period.
British Psychological Society	Guideline	Case Definition	Yes	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 in 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 We agree that it is appropriate not to use the term “Chronic” in relation to Post COVID-19 Syndrome. There are pros and cons of the use of the word “syndrome”. On the one hand, it is consistent with that used other conditions that share some features with Post COVID-19

Stakeholder	Document	Section	Agree with Case Definition	Comment
				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.
MSD Ltd	Guideline	Case Definition	Yes	
Mast Cell Action	Guideline	Case Definition	Yes	These definitions are OK for the moment, I think breaking down the definition of Post Covid 19 into different subsets would be beneficial as more data describing these cohorts is available.
Clinical Advisors to the Scottish Government (Clinical Guidance Cell, Professional Advisory Group)	Guideline	Case Definition	No	While some clinicians supported the case definition as easily understood by patients and clinicians, others were concerned. While appreciating this is arbitrary they were concerned at the defined timelines for a number of reasons: Firstly any person with acute symptoms of illness either physical or mental health related requires appropriate urgent assessment regardless of their COVID diagnosis or not. In particular there is an increased risk of VTE associated with COVID and this may occur at earlier than week 4 so this needs to be stated clearly. Most people with significant viral illness will have not fully returned to health at week 4 post initial symptoms so I think this time point is too early to help with meaningful interventions for additional health care support. I am concerned that this leads to an expectation that people will be returned to full health 2 weeks post initial symptoms and if that isn’t the case potentially overwhelm healthcare services. I understand the need to provide a definition based on times but I would focus more on >12 weeks in terms of providing therapeutic option sat this stage given the lack of evidence.
Long Covid Support Group	Guideline	Case Definition	No	We dispute the premise that the condition divides into three phases (0-4 weeks, 4-12 weeks and 12+ weeks). This appears to imply a linear progression whereby the most severe symptoms are experienced in the acute phase, then gradually tail off. This does not align with the experience of many of the 31,000 members of our Long Covid Support Group: symptoms and signs experienced in the early weeks following infection with SARS-CoV-2 can persist, evolve and/or new ones develop (even after 12 weeks), a relapsing and remitting pattern is common, and symptoms can be more pronounced several weeks or months after infection than they were in the early weeks. We understand the rationale for making reference to two phases to make the distinction between people whose symptoms persist versus those who

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				recover more rapidly, but the guideline should make clear that there may be no difference between symptoms and signs experienced in the acute stage and those experienced weeks or months later. A third, middle phase (4-12 weeks) assumes some physiological transition from one phase to another that neither reflects patient experience nor has any underpinning evidence. The distinction between 'Ongoing symptomatic COVID-19 (Long Covid 4 to 12 weeks)' and 'Post-COVID-19 syndrome (Long Covid 12 weeks or more)' is unclear, especially when 'Post-COVID-19 syndrome may be considered before 12 weeks while the possibility of an alternative underlying disease is also being assessed'. What does this mean? And why the 12 week cut off point? This is an arbitrary cut off as new pathologies can arise before or after this time. What if the patient has not managed to access assessment before 12 weeks: will they automatically get the 'diagnosis' of post Covid syndrome? What assessment is necessary at that point if they have not had it before this? We reject unequivocally the term 'Post Covid Syndrome'. The Long Covid term, originally developed by Dr Elisa Perego, an Italian academic with the condition, is well established in the U.K. and internationally, and reflects the only certainty about the condition, i.e. that symptoms can endure. In contrast to 'Post Covid Syndrome', Long Covid is an open term that makes no assumptions as to the persistence of the virus. The rationale given for creating a new term 'Post Covid Syndrome' is contradictory and flawed, since it can be argued that 'post' is also a time-specific term. The name Long Covid has the advantage that it will not become obsolete as new research findings emerge. Using post-Covid syndrome risks making the guideline out of date very rapidly. Using post-covid-19 syndrome also risks alienating the large and growing international community of people with Long Covid. The imposition by the medical establishment of an unwanted name, that contradicts the lived experience of patients, flies in the face of the principle in the NHS England constitution that 'patients will be at the heart of everything the NHS does'.
Neurological Alliance	Guideline	Case Definition	Yes	
NHS England and Improvement	Guideline	Case Definition		There should be some explanation regarding, for example, patients within critical care who have been admitted in an acute episode and remain in critical care for over 12 weeks.

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Association of British Neurologists	Guideline	Case Definition	Yes	please consider those testing negative but with 'symptomatic long-covid', in light of unreliability of tests. also consider hospital and community testing as separate group
Royal College of Speech and Language Therapists (RCSLT)	Guideline	Case Definition	No	See our comments referring the the core MDT.
Public Health England	Guideline	Case Definition	No	No, as the definition “Signs and symptoms that develop during or following an infection consistent with COVID-19” is not specific enough.
Royal College of Pathologists	Guideline	Case Definition	No	"It is clear that an immense amount of effort has gone into compiling two substantive documents which have been issued for pre-consultation. In addition, the listing of the included studies and the evidence tables are both informative, useful to those of us who try and keep up with the literature and extremely interesting, clearly exemplifying the depth to which the authors went to compile the reports. The principal document, ""Management of long-term effects of covid-19"" is a valuable dissertation on the broadness of the symptomatology of this disease. It brings a welcome and rational approach to defining an extended period of symptomatology within the diagnosis of Covid 19 and leading to a working differentiation between the ""acute disease Covid 19"" which is considered to be coherent up to the end of four weeks, ongoing symptomatic illness from 4 weeks to twelve weeks ""long Covid 19"", illness extending beyond 12 weeks ""Post Covid 19"". The development of this approach to SARS CoV 2 associated disease and the terminology it brings are a welcome analytical approach. However, from a question of the pathological phenotype of prolonged symptomatology, there is a real concern that this does not take into account the need for diagnostic accuracy. This concern applies also to the Equality Impact Assessment document, nevertheless also a well written, informative and useful paper. To imply that it is sufficiently accurate for clinical practice to consider that the patient presenting with symptoms which are ""consistent with the diagnosis of Covid 19"" has been infected by SARS CoV 2 is simply incorrect. The very diffuse symptomatology generated by SARS CoV 2 infection may be sufficient for inducing the necessary self-solation but is not sufficient for making an accurate diagnosis of viral infection. In order both better to

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				understand post Covid 19 disease and provide appropriate care for patients with this pathology a diagnosis of viral infection is required. In the acute presentation of symptoms consistent with infection the diagnosis should be made by detection of viral antigen or viral genome in respiratory tract fluid. Additionally, in patients with more severe disease requiring hospitalisation a viraemia may be detectable at the time of presentation and, depending upon the duration of illness prior to presentation, acute phase serology, preferably including IgM class antibody detection, may also confirm acute viral infection. If there has been a delay in presentation the detection of viral infection by PCR or antigen detection may not be possible and the detection of seroconversion is the preferred diagnostic modality. Furthermore, if one is intending to give a patient the diagnosis of post Covid 19 which may also suggest to the patient the concept of resistance to further infection, then it would seem wise to use the presence of detectable antibody to confirm the diagnosis of previous SARS CoV 2 infection. It needs to be borne in mind that only appropriate tests should be used, those which have been identified to display insufficient sensitivity in the late convalescent phase or have poor specificity must be avoided.
National Voices	Guideline	Case Definition	No	We are aware that there seems to be a preference for Long Covid – as opposed to post-Covid syndrome or the like amongst people who have experience of living with ongoing Covid symptoms. We think we should use this label since it seems to resonate with their experience of this being an ongoing problem without implying that it will be chronic or that one phase necessarily always follows another. We think it is one of the examples where privileging the lived experience of people over the absence of firm professional knowledge or consensus makes sense.
University Hospitals Coventry and Warwickshire NHS Trust	Guideline	Case Definition	Yes	
POTS UK	Guideline	Case Definition	Yes	We agree that post-covid is preferable to long-covid which has connotations about duration and relatedly recovery.
Long Covid SOS	Guideline	Case Definition		p15 Line 1 If the term 'Post Covid syndrome' can be used across these four entities, then surely so can 'Long Covid'? Long Covid is a patient made term and there is considerable

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				community distress that this has been rejected as a term. p15 Line 7 Patients agree that 'Long Covid' is an 'umbrella' term which is why it is so useful. We as yet have no evidence that the four entities are medically different even if they seem to present in different ways. Even so, there are many conditions which have an accepted name but which contain different variants within it - e.g. Diabetes, Inflammatory Arthritis p15 Line 13 It is this definition, at 12 weeks or longer, which would lend itself to the term 'Long Covid' - it would be a compromise which is likely to be welcomed by patients p15 Line 19 However this explanation relies on some agreement as to the term 'acute phase'. What does this actually mean? Do we know that people are no longer in an infectious state as one of the theories is viral persistence? Many people see little change or alleviation in their symptoms after 4 weeks or less, for some the symptoms become worse. In general, patients do not feel that anything has 'ended' and therefore the word 'post' is meaningless. p16 Line 4 I do not think this is written correctly. Sufferers were being told by the Government and media outlets that they should be recovered in 2-3 weeks. There was no recognition until Long Covid sufferers engaged with the media that recovery could be longer. It was a binary between severe and potential death and mild. Do not medicalise the emotional distress felt due to being abandoned in the community with no support. p19 Line 3 Excellent this is essential p19 Line 17 This supports the need for early referral to mdt clinics - before 12 weeks if possible p20 Line 14-16 What was the agreement - that they were of value? Some people are unable to maintain daily logging/diary completion and so shouldn't be made to feel they are essential to their recovery
Long Covid Support Group	Guideline	Case Definition		Page 14, lines 22-23: 'The significant progress made by patient groups using the term 'long COVID' was recognised and incorporated into the definition' feels patronising and tokenistic. Why not call it Long Covid, and include 'post-Covid syndrome' in inverted commas as a nod to those who prefer that term? Page 15, line 1: The NIHR Themed review cited did not refer to 4 syndromes: 'there is a possibility that the symptoms described may be due to a number of different syndromes (e.g. Post-Intensive Care syndrome, Post-Viral Fatigue syndrome and Long-Term Covid syndrome). Some people may be suffering with more than one syndrome at the same time.' https://evidence.nihr.ac.uk/themedreview/living-with-covid19/ Page 15, lines 4-5: Post-Covid-19 syndrome has been used in multiple ways in the literature and media. This, in itself, is not a reasonable rationale for accepting or rejecting a name. Page 15, lines 5-7: Disagree that using the term Long Covid [please use capital L] 'alone for the

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				basis of the clinical guideline may have confusing consequences for patient and clinicians alike' and that Long COVID 'as a standalone term has already been used in multiple different ways across the literature'. Page 15, line 9: What are the specific clinical criteria for Post-Covid-19 Syndrome and where is the evidence based rationale? Page 15, line 11: Codes can be developed for whatever we define. Justifying calling a disease by a particular name because of the need for codes is the tail wagging the dog. What's wrong with Acute Covid (0-4 weeks), Long Covid (5-12 weeks) and Long Covid (>12 weeks)? Page 15, lines 12-13: We dispute the premise that the condition divides into three phases (0-4 weeks, 4-12 weeks and 12+ weeks). This appears to imply a linear progression whereby the most severe symptoms are experienced in the acute phase, then gradually tail off. This does not align with the experience of many of the 31,000 members of our Long Covid Support Group: symptoms and signs experienced in the early weeks following infection with SARS-CoV-2 can persist, evolve and/or new ones develop (even after 12 weeks), a relapsing and remitting pattern is common, and symptoms can be more pronounced several weeks or months after infection than they were in the early weeks. We understand the rationale for making reference to two phases to make the distinction between people whose symptoms persist versus those who recover more rapidly, but the guideline should make clear that there may be no difference between symptoms and signs experienced in the acute stage and those experienced weeks or months later. A third, middle phase (4-12 weeks) assumes some physiological transition from one phase to another that neither reflects patient experience nor has any underpinning evidence. Page 15, line 13: We reject unequivocally the term 'Post-Covid-19 Syndrome'. The Long Covid term, originally developed by Dr Elisa Perego, an Italian academic with the condition, is well established in the U.K. and internationally, and reflects the only certainty about the condition, i.e. that symptoms can endure. In contrast to 'Post-Covid-19 Syndrome', Long Covid is an open term that makes no assumptions as to the persistence of the virus. The rationale given for creating a new term 'Post-Covid-19 Syndrome' is contradictory and flawed, since it can be argued that 'post' is also a time-specific term. The name Long Covid has the advantage that it will not become obsolete as new research findings emerge. Using Post-Covid-19 syndrome risks making the guideline out of date very rapidly. Using Post-Covid-19 syndrome also risks alienating the large and growing international community of people with Long Covid. The imposition by the medical establishment of an unwanted name, that contradicts the lived experience of patients, flies in the face of the principle in the NHS

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				England constitution that 'patients will be at the heart of everything the NHS does'. The distinction between 'Ongoing symptomatic COVID-19 (Long Covid 4 to 12 weeks)' and 'Post-COVID-19 syndrome (Long Covid 12 weeks or more)' is unclear, especially when 'Post-COVID-19 syndrome may be considered before 12 weeks while the possibility of an alternative underlying disease is also being assessed'. What does this mean? And why the 12 week cut off point? This is an arbitrary cut off as new pathologies can arise before or after this time. If the patient has not managed to access assessment before 12 weeks will they automatically get the 'diagnosis' of post Covid syndrome? What assessment is necessary at that point if they have not had it before this? Page 15, lines 14-26: 'Ongoing' or 'post' are no less time specific than 'chronic' or 'persistent', which were rejected on this basis. The title of the document refers to 'long-term'. Post-Covid-19 syndrome (12 weeks) and ongoing symptomatic Covid (4-12 weeks) 'diagnoses' are time based, so this argument does not hold up. Long Covid implies no particular timeframe. Page 15, line 19: Reference to the acute stage of the illness ending makes assumptions about the natural history of the condition that have not yet been confirmed by research. If the guideline argues that use of 'the term post recognised that the acute phase of the illness has ended', it could be interpreted that up until 12 weeks a patient is still in the 'acute' phase. Also if it is 'not possible to determine how long the ongoing effects will last' (page 15 line 16), how is it possible to justify a time restricted ongoing symptomatic phase? There is evidence of persistent infection or acute disease after 12 weeks. These studies evidence persistent infection 1,2 and ongoing pathology 3–6 in patients beyond 3 months which contradicts the premise for the term 'post acute'. The term post acute has no logic given the aforementioned literature 1. Gaebler, C. et al. Evolution of Antibody Immunity to SARS-CoV-2 1 2. bioRxiv 2020.11.03.367391 (2020) doi:10.1101/2020.11.03.367391. 2. Dias De Melo, G. et al. COVID-19-associated olfactory dysfunction reveals SARS-CoV-2 neuroinvasion 2 and persistence in the olfactory system 3 4 Short title: SARS-CoV-2 neuroinvasion and persistence 5 6. bioRxiv 2020.11.18.388819 (2020) doi:10.1101/2020.11.18.388819. 3. Dennis, A., Mbbch, J. A., Badley, A. D., Anton, G. & Mbbch, D. Multi-organ impairment in low-risk individuals with long COVID. Barts Heal. NHS Trust 2020.10.14.20212555 (2020) doi:10.1101/2020.10.14.20212555. 4. Carfì, A., Bernabei, R. & Landi, F. Persistent symptoms in patients after acute COVID-19. JAMA - Journal of the American Medical Association vol. 324 603–605 (2020). 5. Puntmann, V. O. et al. Outcomes of Cardiovascular Magnetic Resonance Imaging in Patients Recently Recovered from

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				Coronavirus Disease 2019 (COVID-19). JAMA Cardiol. (2020) doi:10.1001/jamacardio.2020.3557. 6. Sartoretti, E., Sartoretti, T., Imoberdorf, R., Dracklé, J. & Sartoretti-Schefer, S. Long-segment arterial cerebral vessel thrombosis after mild covid-19. BMJ Case Reports vol. 13 236571 (2020). Page 15, line 26: Considered the appropriate choice by who? If your choice is wholeheartedly rejected by the wider community of people with Long Covid, then in what sense is it the appropriate choice? Page 16, line 2: Why only ‘after acute COVID-19’? Replace with ‘after infection with SARS-CoV-2’? Page 16, line 3: Replace ‘after’ with ‘during’. Page 16, line 12: Remove mention of phone or video appointments to allow the practitioner and patient to agree the best way, which could include face-to-face. Page 16, line 17: Yorkshire tool is based on activities of daily living after ICU. Not relevant to most people with Long Covid symptoms as there is no assessment of organ damage. Page 16, line 19: Remove the word ‘ideally’. Page 16, lines 20-22: Rephrase to remove reference to age groups: The panel highlighted that some people may report different symptoms to those most commonly reported.’ Page 16, lines 23-28:Why should someone with Long Covid symptoms serious enough for them to seek medical attention be treated differently to anyone else in their ability to access face-to-face appointments? The recommendation for an initial screening consultation feels discriminatory. Page 17, lines 11-17: Make clear that longer appointment times may be required to allow discussion of complex symptoms and their progression. Page 17, line 19: Remove ‘, particularly older people’. Page 18, lines 22-27: There also seems to be a physiological basis to some mental health symptoms, for example many people with Long Covid report that their adrenal system/sympathetic nervous system seems to be activated on a prolonged basis. This can cause insomnia, cognitive impairment as well as feelings of anxiety. Also, there is no evidence of higher rates of anxiety and depression among people with Long Covid than in the general population. Page 19, line 8: Disagree with the statement, ‘not enough evidence to recommend specific criteria for referral.’ This statement is not true or safe, given the emerging picture of organ damage and ongoing inflammatory reactions. Specific referral criteria could be drawn for each body system affected, and there should be a low threshold for referral in the context of a new virus. These criteria for referral should be made as a priority: otherwise there is high risk of physical pathology being missed. P20, lines 2 & 11: Replace ‘brain fog’ with ‘cognitive impairment’ (which can include difficulty in concentrating and/or retaining information, problems with finding the correct words and/or spelling, and

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				sensory overload). P20, line 3: Using language such as ‘goals’ risks people pushing themselves (potentially triggering worsening of symptoms) and also feeling a failure if goals are not achieved. Page 20, lines 10-13: What is ‘the evidence’? This list should include chest pain, muscle and/or joint pain, insomnia, exercise intolerance, menstrual changes.