NG188 Managing the long-term effects of COVID-19: update
Targeted consultation on draft guideline
Comments table
14/09/2021-27/09/2021

Stakeholder	Document	Section	Recommendation (original guideline number where applicable)	Comments
Welsh Government	Guideline	Identification	1.1 [UPDATED] Give people...advice and written information…	Agree – but suggest that this should be a consistent standardised message, with local information if appropriate and relevant
Faculty of occupational medicine (FOM)	Guideline	Identification	1.1 [UPDATED] Give people...advice and written information…	It would be useful to mention the specific expertise offered by occupational health professionals in supporting advice to individuals and employers in relation to adjustments to work to support rehabilitation and recovery. Informational management can be helpful in managing uncertainty so would this be a consistent package of care/ resources + to include information about psychological impacts and when to seek additional support
Royal College of Speech and Language Therapists (RCSLT)	Guideline	Identification	1.1 [UPDATED] Give people...advice and written information…	The RCSLT welcomes the addition of "return to work or education". People with experience of voice issues months after contracting COVID-19 have spoken out about the detrimental impact on their ability to return to work (Chaudhry et al, 2021). The RCSLT found that people post-COVID reported their speech and language therapy needs did impact on their ability to return to work. (Long COVID and speech and language therapy: Understanding the mid- to long-term speech and language therapy needs and the impact on services, 2021).
Public Health England	Guideline	Identification	1.1 [UPDATED] Give people...advice and written information…	The point 'if new or ongoing symptoms occur they can change unpredictably, affecting them in different ways at different times' does not appear to provide useful information and may result in negative expectations and have negative health outcomes. The decision has been taken not to state risk factors for Long COVID (due to lack of evidence). Given that there is some (low quality) evidence that hospitalisation is a risk factor, potentially for particular Long COVID symptoms or more severe Long COVID symptoms, is it accurate to say "the likelihood of developing ongoing symptomatic COVID-19 or post-COVID-19 syndrome is not considered to be linked to the severity of their acute COVID-19 (including whether they were in hospital)" (recommendation, bottom of page 14). Given the lack of good quality evidence (noted in the review), and the decision not to highlight risk or

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				protective factors on this basis, is it premature / potentially misleading to make this statement. Regarding the section on Page 15 which states that advice on symptoms to look out for was removed, because the list is too long to give people helpful information about symptoms to look out for. Why is the long list of symptoms still included? It would be helpful to refine the list of symptoms – the list at the moment is so long, and so broad, it is only likely to encourage people to attribute any symptoms they are experiencing to Long COVID, it is not likely to be helpful to identify whether people are actually experiencing Long COVID. [advice from PHE Behavioural Insights Team]
Royal College of Occupational Therapists	Guideline	Identification	1.1 [UPDATED] Give people...advice and written information…	This information should be co-produced with people with lived experience and representatives of diverse communities, and needs to be available in different languages and formats, and written with regard to health literacy. The rationale notes that it is important for people to know when to contact a health professional e.g. if they are struggling to return to work or education. It will be beneficial to give greater clarity on which professionals can be contacted e.g. occupational therapists, vocational rehabilitation services and occupational health services, and how they can be contacted.
UK Doctors Long Covid	Guideline	Identification	1.1 [UPDATED] Give people...advice and written information…	This assumes there is good, clear information available for GPs and clinicians managing people with Long Covid to access – is this available?
Asthma UK and the British Lung Foundation	Guideline	Identification	1.1 [UPDATED] Give people...advice and written information…	Whilst we believe that it is important to acknowledge that self-management may not be possible or appropriate for everyone, we do largely agree with the updated recommendation. Any additional information that can be provided to people with Long Covid-related breathlessness to manage symptoms or obtain further support is welcome. This is primarily because we have heard through our insights work, that people with Long COVID symptoms may not be accessing information that can help them with their recovery. In an Asthma UK and the British Lung Foundation Long COVID survey conducted in August 2021, we asked people about the quality of spoken and written communications they received from different healthcare professionals. We asked respondents whether they had

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				spoken to their GP or nurse about the things that have affected them after they had symptoms of COVID-19, of which: 64.2% said yes 35.8% said no When asked whether their GP or nurse told them about things they can do to help their recovery: Over half of respondents (58%) said no Just shy of a third said yes (32%) 9.6% of respondents said that they do not know Similarly, when asked whether they found the information they received helpful for managing their condition at home: Over half of respondents (51.4%) said that no information was provided A quarter of respondents (25.4%) stated that it was fairly helpful 15.3% of respondents said that it was not at all helpful Only 7.9% of respondents said that it was very helpful. Access to high-quality information and support is imperative in helping people manage their conditions well – particularly for people with ongoing symptomatic and post-COVID syndrome, whose symptoms may fluctuate and change over time. Asthma UK and the British Lung Foundation have developed Long COVID resources that cover symptoms, diagnosis, treatment and the support available for individuals recovering from Long COVID (Long COVID Recovery Support Programme | British Lung Foundation (blf.org.uk)). We would be pleased to have this content shared in any guidance produced by or for healthcare professionals who may wish to signpost their patients presenting with Long COVID related breathlessness, to additional resources and support.
Polymyalgia Rheumatica and Giant Cell Arteritis Scotland (PMR-GCA Scotland)	Guideline	Identification	1.1 [UPDATED] Give people...advice and written information…	Medical consultations are times of high stress for patients, especially those who are ill/suffering from "brain fog". Because of this written information is essential if it is to be remembered correctly and discussed with family/carers.

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Public Health Scotland	Guideline	Identification	1.1 [UPDATED] Give people...advice and written information…	When written advice is suggested it would be useful to link to some recommended sources of this – like MY COVID recovery, or other resource
Long COVID Scotland Action Group	Guideline	Identification	1.1 [UPDATED] Give people...advice and written information…	• Good that this section includes families and carers and essentially good information but there is some bias. • Would be worth mentioning employment/caring/education here – these are key issues. • 'Including whether patients were in hospital' needs to be more overt to avoid bias, as being in hospital is considered the default. Most cases were people who were not in hospital. • Front and central to this section should be life threatening symptoms such as chest pain, breathing difficulties, including myocarditis, pericarditis and ongoing clots (including the possibility of microclots) and pneumonia. Focusing on self-management implies that Long Covid is more benign than it is. • Links within this section are not working, so we cannot comment on them.
Long COVID Physio	Guideline	Identification	1.1 [UPDATED] Give people...advice and written information…	Page 14: The list of common symptoms should include post-exertional symptom exacerbation based on: - Literature on common symptoms including post-exertional symptom exacerbation; https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370(21)00299-6/fulltext https://www.medrxiv.org/content/10.1101/2021.06.11.21258564v1.full.pdf - Literature on aetiology and mechanisms of exercise intolerance; https://journal.chestnet.org/article/S0012-3692(21)03635-7/fulltext - CDC guidelines including post-exertional symptom exacerbation; https://www.cdc.gov/coronavirus/2019-ncov/hcp/clinical-care/post-covid-conditions.html - Rehabilitation briefing papers, standards and guidelines specifically referencing post-exertional symptom exacerbation; https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-2021_0.pdf https://www.albertahealthservices.ca/assets/info/ppih/if-ppih-covid-19-rehab-allied-health-practice-considerations-post-covid.pdf#page38 https://physiotherapy.ca/sites/default/files/site_images/Advocacy/long_covid_en-final-rev2.pdf

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				https://www.csp.org.uk/system/files/publication_files/001745_Community%20Rehab%20Standards_A4_V7.pdf https://www.csp.org.uk/system/files/publication_files/001745_Hospital%20Standards_A4_V10_3.pdf https://apps.who.int/iris/bitstream/handle/10665/344472/WHO-EURO-2021-855-40590-59892-eng.pdf?sequence=1&isAllowed=y The list of common symptoms should also include inappropriate tachycardia as associated with dysautonomia (and/or orthostatic intolerance) in the cardiovascular and neurological symptom sections, based on the prevalence in the expert testimony (Gp Capt Edward Nicol QHS), the same rehabilitation documents outlined above, and the following evidence: https://www.cdc.gov/coronavirus/2019-ncov/hcp/clinical-care/post-covid-conditions.html https://internal-journal.frontiersin.org/articles/10.3389/fneur.2021.624968/full https://link.springer.com/article/10.1007/s12026-021-09185-5?fbclid=IwAR054Og-JQV1WLtLUiM3tt1dGDzg41UhSy6yMd5ht_AQjXjm9eL6vKQoeq8 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7685310/ https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7976723/ Page 15: Recommendations on self-management and supported self-management should include updated 2nd edition WHO Europe guidance https://apps.who.int/iris/bitstream/handle/10665/344472/WHO-EURO-2021-855-40590-59892-eng.pdf?sequence=1&isAllowed=y Page 15: The sentence “This could help to relieve anxiety if people do not recover in the way they expect.” Is an assumption not based within evidence. Information is required irrespective of cause/effect of mental and emotional health symptoms and impairments. There is no evidence to suggest that information alleviates anxiety when living with Long COVID. We suggest this sentence should be reworded to be a fair reflection of the evidence within the rationale. It could be advised to suggested use an alternative sentence instead such as: “this could help support people with symptom management and recovery”.

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Patient-Led Research Collaborative	Guideline	Identification	1.1 [UPDATED] Give people...advice and written information…	Instead of saying that for "many" people, symptoms will resolve by 12 weeks, provide exact statistics from ONS or say "some" in order to avoid providing a false perspective of how many are recovered by 12 weeks. The list of symptoms provided must include post-exertional malaise as this is one of the most common symptoms and changes the course of treatment for many patients. Add resources from Long Covid Physio and PCOT on activity management, energy conservation, and pacing. Advice for patients on managing common symptoms is available from: the websites of Long Covid Physio, RCOT and LongCovid.org.
The National Guideline Centre (ME/CFS guideline committee)	Guideline	Identification	1.1 [UPDATED] Give people...advice and written information…	The recognition of the impact of returning to work or education is welcomed.
The National Guideline Centre (ME/CFS guideline committee)	Guideline	Identification	1.1 [UPDATED] Give people...advice and written information…	The recognition of the impact of returning to work or education is welcomed.
Sheffield ME and Fibromyalgia Group (inc long COVID)	Guideline	Identification	1.1 [UPDATED] Give people...advice and written information…	We welcome patients being advised about the unpredictability of symptoms and of their possible journey to recovery which may include periods of deterioration of symptoms and will not be linear.
Royal College of Paediatrics	Guideline	Identification	1.1 [UPDATED] Give people...advice and written information…	Please add: • New or ongoing symptoms may occur several weeks after a mild or asymptomatic infection • Symptoms may follow a relapsing and remitting course over time. - Change “struggling to return to work or education” to “struggling to attend work, education

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and Child Health				or recreational activities". - Instead of recovery time is different for everyone but for many people symptoms will resolve by 12 weeks. - Suggest replacing many with most? - Suggest adding that is some cases patients recover from acute infection and develop post COVID-19 symptoms after a gap after weeks of being well. - As it's a CYP guideline suggest write school or education or work rather than "poor performance at work or education" both times when used in the rationale paragraph, also used in the box at top of page. - Suggest somewhere that if symptoms affecting ability to access education, recreational activities should seek help.
Long Covid Support	Guideline	Identification	1.1 [UPDATED] Give people...advice and written information…	When providing people with information on 'what they may expect from recovery' - how are you defining recovery? Signpost to extremely useful resources from Long Covid Physio and RCOT on activity management, energy conservation and pacing. Advice for patients on managing common symptoms is available from: the websites of Long Covid Physio, RCOT and LongCovid.org, the website of charitable organisation Long Covid Support. The advice on 'Getting moving again' on the YCR website is inappropriate and represents a patient safety issue - pulmonary rehab is not appropriate for Long Covid which is an energy limiting condition and requires careful assessment for post exertional symptom exacerbation and dysautonomia, followed by a pacing/energy conservation approach in the majority of patients. Consider advising on the importance of rest, pacing, sleep, hydration and diet (avoiding caffeine, sugar), and that new allergies and intolerances may develop. Meditation and breathwork can be helpful. Advice around if and when it is appropriate to return to any exercise is essential to prevent harm. Individualized Advice may be needed on setting realistic goals for recovery as this can be very difficult for people coming to terms with new chronic illness and is often dependent on the heterogeneity of the symptoms as well as social pressures, e.g. finance, work, education, caring responsibilities. Its important to let patients and healthcare professionals better understand the unpredictability and possibility of new symptoms. suggest changing wording of bullet "new symptoms may occur and both new and ongoing symptoms may change upredicably, affecting …..".Consider the role of

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				patient support groups in providing advice and supportive validation. What advice is being given and is this co-produced with patient advocates? Do GPs have access to good quality information? If so, from where are they getting it? Has such information been genuinely and meaningfully co-produced by people with lived experience? It is essential that post exertional malaise is included in the list of common symptoms. We don't understand why it is not mentioned in this guideline as it is a common symptoms reported by people with Long Covid and harm could be done if people and HCPs are not aware of it.
Long Covid Wales	Guideline	Identification	1.1 [UPDATED] Give people...advice and written information…	Individuals who have been infected with SARS-CoV-2 and who have not developed acute COVID-19, but nonetheless go on to develop Long COVID/post-COVID are now well described, so this possibility should be given for medical practitioners to consider the possibility.
British Thoracic Society	Guideline	Identification	1.1 [UPDATED] Give people...advice and written information…	The statement regarding the development of ongoing symptomatic COVID-19 is not related to the acute severity of COVID-19 including whether hospitalised is incorrect. People admitted to hospital are much more likely to suffer on going symptoms than in those patients managed in the community. Epidemiological studies including both community and hospital managed patients report a higher OR for prolonged symptoms in those hospitalised. More recent ONS data reports a prevalence of 5% of Long Covid. Recent published data from Wuhan China Lancet 2021 reports ongoing symptoms in 49% of those hospitalised at 12 months (n>1200). UK data from the PHOSP-COVID studies highlights only 30% of people are fully recovered at 6 months after discharge (Preprint on medrxiv, accepted LRM Aug 2021) . Suggest removing this bullet point unless it states that post-COVID-19 syndrome is more likely post-hospitalisation
NHSEI - Specialised commissioning	Guideline	Identification	1.1 [UPDATED] Give people...advice and written information…	Advice and written information provided must be communicated in a culturally competent manner, in particular paying attention to the risk of digital exclusion.

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NHSEI - Specialised commissioning	Guideline	Identification	1.1 [UPDATED] Give people...advice and written information…	I would add that it is important to give advice re how to manage recuperation (gradual return to exercise and other activity as their symptoms resolve).
NHSEI - Specialised commissioning	Guideline	Identification	1.1 [UPDATED] Give people...advice and written information…	Add advice on how to manage recovery such as advice on gradual incremental steps to increasing exercise capacity. Without this there is a risk of nurturing de-conditioning
Welsh Government	Guideline	Identification	[NEW] Give people information on COVID-19 vaccines...	Agree - but again would suggest standardised messaging.
Royal College of General Practitioners	Guideline	Identification	[NEW] Give people information on COVID-19 vaccines...	Can the committee consider adding more information here? The link provided within the guidance does not provide any information regarding the safety of the vaccines for patients suffering the long-term effects of COVID-19. In order to reassure patients, or at least recognise that research is underway, we think it would be useful to include some further information regarding the safety of vaccines for these patients and acknowledging any side effects they may experience.
Public Health England	Guideline	Identification	[NEW] Give people information on COVID-19 vaccines...	This advice is for children and young people. Should this recommendation mention that vaccination should be encouraged for those age groups it is recommended/licensed. E.g. Are you asking healthcare professionals to encourage vaccination in a 1 year old?
Royal College of Occupational Therapists	Guideline	Identification	[NEW] Give people information on COVID-19 vaccines...	As noted previously, this information should be co-produced with people with lived experience, and representatives of diverse communities, as well as being available in different languages and formats, and written with regard to health literacy.
Asthma UK and the British Lung Foundation	Guideline	Identification	[NEW] Give people information on COVID-19 vaccines...	Whilst we recognise that more conclusive evidence is needed to understand the impact of COVID-19 vaccines on the long-term effects of COVID-19, we support the recommendation to encourage people with Long COVID symptoms to have the vaccination to prevent acute COVID-19 infection. We also agree that in doing so, it will be important to explain to

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				patients that the impact of vaccines on ongoing symptomatic and post-COVID symptoms are still unknown.
Public Health Scotland	Guideline	Identification	[NEW] Give people information on COVID-19 vaccines...	I support the suggestion of giving advice, and encouragement to be vaccinated, but advising 'It is not known of effect of vaccination on symptoms' must be done with caution so that message isn't seen to endorse any vaccine safety myths i.e 'people are being used a guinea pig'. Messaging must not disprupt vaccine confidence. ? Reframe this sentence – i.e. 'evidence is till emerging', or 'there is no evidence yet to suggest an effect'.
PACS19 Post Acute Covid Syndrome 19 support group	Guideline	Identification	[NEW] Give people information on COVID-19 vaccines...	No research has been conducted on the risk to longhaulers and vaccines eg the risk of clots. An observational study was done across some groups but very small in scale and much more work is needed in this area before it should be inlcuded in a guideline. It smacks to patients of people being forced into a vaccination drive without correct infromation that could put them in harms way. Given many patient support groups report mostly negative impacts of the vaccines (single and double dose) and only a minority experiencing a few temporary postiive effects we are aghast at its inclusion. this could potentially be putting patients at risk . Such a statement only serves to instill fear and conspiracy theories.
Long COVID Scotland Action Group	Guideline	Identification	[NEW] Give people information on COVID-19 vaccines...	• Please note all comments below are from a pro-vaccine position – vaccines are essential to ending the pandemic. • This section needs to be about more open and honest conversation about the benefits but also the possible risks of vaccines on Long Covid. • While vaccines are essential, their effects are not unknown. In France, pre-existing active myocarditis or pericarditis (common in LC, cardiac abnormalities are at about 30% and not always apparent until echo and sometimes even MRI have been performed) and MISC are considered to be vaccine contraindications, given recent reports of myocarditis from the Pfizer and Moderna vaccines. Cardiologists in London are also following this advice – this needs to be considered urgently. • MCAS symptoms and other mast-cell issues are common in LC, including anaphylaxis – this may need to be discussed prior to vaccination. • It is known within Long Covid communities (most of which are strongly pro-science

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				including pro-vax) that the vaccine can have a range of effects on Long Covid – this has also been studied and people have submitted yellow cards. Patients consulting with their doctors will therefore have understandable vaccine hesitancy and may have done their own research, so if a doctor says 'it is not known' the patient will feel unheard. • Patients need to be allowed an open and honest conversation about whether the vaccine is the right choice for them; most will probably proceed if they know they are cared for.
Long COVID Physio	Guideline	Identification	[NEW] Give people information on COVID-19 vaccines...	Page 22: Benefits and harm; The sentence "The panel considered that the results from the existing studies were inconclusive and agreed that there remains uncertainty for the outcomes of change in ongoing symptoms, quality of life and mental wellbeing." should include functioning and disability in the list of outcomes. Page 22: Certainty of the Evidence; The sentence "The certainty of the evidence for outcomes of change in symptoms, quality of life and mental wellbeing is very low." should include functioning and disability in the list of outcomes. Page 22: Preference and values; The sentence "These included all-cause adverse effects, change in symptoms, quality of life and wellbeing." should include functioning and disability in the list of outcomes. Page 27: Summary Pre-Vaccination Infection; The sentence "Evidence for change in symptoms, quality of life and mental wellbeing post-vaccination" should include functioning and disability in the list of outcomes. Rationale: Functioning is the 3rd health indicator (alongside mortality and morbidity) for monitoring the performance of health strategies in health systems, and a priority of the World Health Organization. https://pubmed.ncbi.nlm.nih.gov/28118696/ https://www.who.int/initiatives/rehabilitation-2030 Page 22: Is there value in identifying the potential risk of menstrual changes after COVID-19 vaccination, considering more women are affected by Long COVID than men? https://www.bmj.com/content/374/bmj.n2211
Long Covid SOS	Guideline	Identification	[NEW] Give people information on COVID-19 vaccines...	This section does not reflect the very real concerns that some of those with lived experience have about vaccines. There were concerns in the community about worsening of symptoms, the recommendation of the vaccine brand depending on possible side effects

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				and Long Covid symptoms, as well as alleviation of symptoms. More research in this area around the effects on those with Long Covid would be especially welcomed.
Patient-Led Research Collaborative	Guideline	Identification	[NEW] Give people information on COVID-19 vaccines...	Acknowledge that symptoms may temporarily improve or worsen following vaccination, but that the extent to which this happens and for who is not yet known. Acknowledge that the best way to prevent Long Covid is to prevent infection with SARS-CoV-2.
Sheffield ME and Fibromyalgia Group (inc long COVID)	Guideline	Identification	[NEW] Give people information on COVID-19 vaccines...	We support this advice as there is insufficient known yet about who responds badly to the vaccine.
Royal College of Paediatrics and Child Health	Guideline	Identification	[NEW] Give people information on COVID-19 vaccines...	Vaccination should only be given according to existing policy according to age as persistent symptoms after COVID are not an independent indication for vaccination (i.e., not currently recommended under 12 years).
Long Covid Support	Guideline	Identification	[NEW] Give people information on COVID-19 vaccines...	Ensure that people are aware that symptoms may temporarily improve or worsen following vaccination, but that the extent to which this happens and for who, is not yet known. Please advise people who menstruate of the risk of impact to their menstrual cycle length, flow or symptoms, as increased pain in particular is likely to exacerbate post-COVID-19 syndrome. Messaging around the vaccine should focus on the fact that the best way to prevent Long Covid is to prevent infection with SARS-CoV-2 (including break-through) infections.
Long Covid Wales	Guideline	Identification	[NEW] Give people information on COVID-19 vaccines...	Given that persons with Long COVID/post-COVID will already have been infected and developed immunity it should be pointed out that vaccination will, in effect, be boosters, so their immunity will be improved and further enhanced by vaccination. However, they will also be at greater risk of well known and described local (e.g. Type III hypersensitivity) and systemic reactions because of their pre-existing immunity, and that if they suffer such effects it is important that these be reported via the Yellow card system to MHRA.

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NHSEI - Specialised commissioning	Guideline	Identification	[NEW] Give people information on COVID-19 vaccines...	Ensuring equitable access for all which may require multi-agency support, involving for example local community groups and faith leaders as key stakeholders. Special consideration should be given to the risk of people living with Long Covid declining Covid and flu vaccines due to the presence of ongoing symptoms. Healthcare professionals can mitigate this risk by clearly explaining the distinction between acute infection symptoms (a caution for vaccination) and Long Covid symptoms (not a caution for vaccination). Herein, advice and written information provided must be communicated in a culturally competent manner, in particular paying attention to the risk of digital exclusion, so that patients can be enabled articulate their situation to their vaccine provider (who may be different to the Long Covid care provider). Or there is a risk that healthcare providers may decline administration of vaccines due to the presence symptoms that are in fact secondary to Long Covid.
NHSEI - Specialised commissioning	Guideline	Identification	[NEW] Give people information on COVID-19 vaccines...	I would make this stronger and highlight that some symptoms of Post COVID syndrome such as breathlessness require observations such as oxygen saturations/ heart rate and are typically best assessed in person.
NHSEI - Specialised commissioning	Guideline	Identification	[NEW] Give people information on COVID-19 vaccines...	Agree
Welsh Government	Guideline	Identification	1.2 [UPDATED] Provide all information in accessible formats...	This should be routine procedure to facilitate understanding and joint decision making
Royal College of General Practitioners	Guideline	Identification	1.2 [UPDATED] Provide all information in accessible formats...	We strongly support the development of information materials in various formats to make sure it is as accessible to as many patients as possible which will enable shared decision making and engage patients in their own care.

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Royal College of Speech and Language Therapists (RCSLT)	Guideline	Identification	1.2 [UPDATED] Provide all information in accessible formats...	NICE's equalities impact assessment clearly highlights that people with disability, communication needs or cognitive impairment are particularly at risk of negative outcomes. The RCSLT strongly recommends that not only should written information be accessible, but all verbally delivered information should be clear, use plain English and avoid jargon. This will prevent people with communication needs having worse health outcomes. The RCSLT would be happy to provide links to websites. Rationale We are concerned that this recommendation is too simplistic. Accessible communication is more than a different format or language. The guideline should clearly state that the best way of communicating is established for each person. Alternative communication methods can include pictures, symbols, large print, Braille, sign language or communications aids, or involving a patient advocate or family member. This would support a more communication-friendly interaction benefitting all people accessing healthcare services.
Royal College of Occupational Therapists	Guideline	Identification	1.2 [UPDATED] Provide all information in accessible formats...	As noted previously, this information should be co-produced with people with lived experience, and representatives of diverse communities, as well as being available in different languages and formats, and written with regard to health literacy.
Asthma UK and the British Lung Foundation	Guideline	Identification	1.2 [UPDATED] Provide all information in accessible formats...	We support this recommendation and believe that content must be offered in accessible formats, enabling people to be well-informed about their own symptoms and the treatment options available to them.
Long COVID Scotland Action Group	Guideline	Identification	1.2 [UPDATED] Provide all information in accessible formats...	• Ironically this is 30 pages into a 76-page document that is unlikely to be read – accessibility needs to be front and centre and this cannot be on the shoulders of GPs who are already so busy – this needs to be provided for them; how are they supposed to find this information in different languages? Completely unrealistic. • Mentioning shared decision making doesn't mean it will happen or that it is necessarily effective for everyone. • Additionally, there are some serious accuracy and stigma issues in the linked documents, esp the patient-information leaflet.

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Long COVID Physio	Guideline	Identification	1.2 [UPDATED] Provide all information in accessible formats...	World Physiotherapy information sheets are freely available in up to 60 different languages and could be considered for inclusion in the provided information. The 5 information sheets cover: - What is Long COVID? https://world.physio/sites/default/files/2021-06/WPTD2021-InfoSheet1-WhatisLongCOVID-Final-A4-v1.pdf - Rehabilitation and Long COVID https://world.physio/sites/default/files/2021-06/WPTD2021-InfoSheet2-RehabandLongCOVID-Final-A4-v1a.pdf - Fatigue and Post-Exertional Symptom Exacerbation https://world.physio/sites/default/files/2021-06/WPTD2021-InfoSheet3-Fatigue-and-PESE-Final-A4-v1.pdf - How to use Pacing https://world.physio/sites/default/files/2021-06/WPTD2021-InfoSheet4-Pacing-Final-A4-v1a.pdf - Breathing Exercises https://world.physio/sites/default/files/2021-06/WPTD2021-InfoSheet5-BreathingExercises-Final-A4-v1_0.pdf All these resources are available in up to 60 languages in the World Physiotherapy toolkit https://world.physio/wptday/toolkit?lang=All&page=0&toolkit_type=1012&year=971 Information sheets in the most common spoken languages globally include: English https://world.physio/toolkit/world-pt-day-2021-information-sheets-english Traditional Chinese https://world.physio/toolkit/world-pt-day-2021-information-sheets-chinese-traditional Hindi https://world.physio/toolkit/world-pt-day-2021-information-sheets-hindi Spanish https://world.physio/toolkit/world-pt-day-2021-information-sheets-spanish Arabic https://world.physio/toolkit/world-pt-day-2021-information-sheets-arabic Bangla https://world.physio/toolkit/world-pt-day-2021-information-sheets-bangla French https://world.physio/toolkit/world-pt-day-2021-information-sheets-french Russian https://world.physio/toolkit/world-pt-day-2021-information-sheets-russian Brazilian Portuguese https://world.physio/toolkit/world-pt-day-2021-information-sheets-brazilian-portuguese Urdu https://world.physio/toolkit/world-pt-day-2021-information-sheets-urdu Indonesian https://world.physio/toolkit/world-pt-day-2021-information-sheets-indonesian German https://world.physio/toolkit/world-pt-day-2021-information-sheets-german Japanese https://world.physio/toolkit/world-pt-day-2021-information-sheets-japanese Korean https://world.physio/toolkit/world-pt-day-2021-information-sheets-korean

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Long Covid SOS	Guideline	Identification	1.2 [UPDATED] Provide all information in accessible formats...	Letters and accessibility of data on appointments and results are not always available. This does not make it easy for the patient to engage in shared decision making. Recommendations on how to improve the access of information on the condition both generalisably and for individual patients, taking into account any previous examinations before the initial assessment, would be welcome due to it's multi-system nature.
Patient-Led Research Collaborative	Guideline	Identification	1.2 [UPDATED] Provide all information in accessible formats...	Define what "accessible formats" are and provide guidelines for how to draft information so people of all health literacy and literacy levels can understand.
Sheffield ME and Fibromyalgia Group (inc long COVID)	Guideline	Identification	1.2 [UPDATED] Provide all information in accessible formats...	We welcome information being provided in a wide range of accessible formats to meet patient needs.
Long Covid Support	Guideline	Identification	1.2 [UPDATED] Provide all information in accessible formats...	The NICE guidelines on patient experience in adult NHS services lists 'people using adult NHS services and their families and carers' under 'who it is for' but the length of the document and volume of information will be inaccessible to most. Do these guidelines exist in a more accessible format for patients to be more easily informed as to what they should expect in terms of patient experience? SIGN's patient booklet on Long COVID does not provide accessible information. It takes 2 clicks to access and 23 pages of information is a lot to read for someone with cognitive impairment. It is far too wordy. You have to get to page 4 before it advises that your healthcare professional will give you information in a format or language that you can understand. You have to have read as far as page 7 to find out that you will be referred urgently to hospital if you have any signs that could be a life-threatening complication. It recommends that you may be required to do an exercise tolerance test, without advising when this may not be appropriate. This accessibility of format needs extending across languages and should include easy read versions that do not neglect complex information needed for informed consent but present it in a way that

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				can be more easily understood. Consider the provision of audio recorded or video formats of key information for those who may struggle to read and digest long passages of text.
Long Covid Wales	Guideline	Identification	1.2 [UPDATED] Provide all information in accessible formats...	Please be aware that the cognitive impairment and "brain fog" with Long COVID/post-COVID are in themselves a disability making it difficult for sufferers to access apps, electronic devices or even comprehend the written or spoken language, so this in itself amounts to an access issue.
NHSEI - specialised commissioning	Guideline	Identification	1.2 [UPDATED] Provide all information in accessible formats...	Advice and written information provided must be communicated in a culturally competent way, in particular paying attention to the risk of digital exclusion
NHSEI - specialised commissioning	Guideline	Identification	1.2 [UPDATED] Provide all information in accessible formats...	I expected to see consideration of ECG in investigations if chest pain or palpitations (and consider acute medical assessment if features of concern) and consider holter monitor if palpitations
NHSEI - specialised commissioning	Guideline	Identification	1.2 [UPDATED] Provide all information in accessible formats...	Agree
Royal College of General Practitioners	Guideline	Identification	1.3 [UPDATED] For people with new or ongoing symptoms…	Can the committee please add more clarity to ensure clinicians confirm that the symptoms the patient is experiencing are, in fact, new. Some patients are presenting to primary care with symptoms that existed prior to COVID-19 and these symptoms risk being attributed to post-COVID syndrome unless this is specifically considered. Can the committee provide further clarity on what it means by 'screening questionnaire', and whether it would be used for screening or case finding? We believe what is meant by this, is to use a standard questionnaire when undertaking a consultation with patients, rather than “screen“ them. However, many of these newly developed questionnaires are limited for use in primary care and are not evidence based and not validated. Can the committee explain why they are being advised over a full history which would be standard practice with any other condition? The push to use these questionnaires is unhelpful for primary care clinicians and patients alike.

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Asthma UK and the British Lung Foundation	Guideline	Identification	1.3 [UPDATED] For people with new or ongoing symptoms…	We agree with this recommendation.
Public Health Scotland	Guideline	Identification	1.3 [UPDATED] For people with new or ongoing symptoms…	Given the increasing number of delayed diagnosis (Cancer, renal failure etc) surely a caveat suggesting that other diagnoses should be excluded/investigated should be added here? There may have been a coincidence in timing of onset of symptoms of a different diagnosis and a recent COVID infection.
Long COVID Scotland Action Group	Guideline	Identification	1.3 [UPDATED] For people with new or ongoing symptoms…	• Even with the evidence cited, this continues to be arbitrary, and concerning as it means patients are less likely to be taken seriously for 3 months – it normalises this recovery time, which is helpful in some respects, but opens up the risk of bias.
Patient-Led Research Collaborative	Guideline	Identification	1.3 [UPDATED] For people with new or ongoing symptoms…	The WHO's clinical case definition will include one definition, not two separate syndromes, for those who are ill for at least 8 weeks. Recommend aligning.
The National Guideline Centre (ME/CFS guideline committee)	Guideline	Identification	1.3 [UPDATED] For people with new or ongoing symptoms…	The case definitions on the three phases (page 4 of the draft guideline document) and recommendation 1.3 (page 31 of the consultation guideline document) have compatibility with the ME/CFS guidance and the times to suspect and diagnose ME/CFS. However, it also demonstrates the potential for confusion between ME/CFS and post-COVID-19 syndrome, with the lack of distinguishing features and the difficulty in diagnosing which is which.
The National Guideline Centre (ME/CFS guideline committee)	Guideline	Identification	1.3 [UPDATED] For people with new or ongoing symptoms…	The case definitions on the three phases (page 4 of the draft guideline document) and recommendation 1.3 (page 31 of the consultation guideline document) have compatibility with the ME/CFS guidance and the times to suspect and diagnose ME/CFS. However, it also demonstrates the potential for confusion between ME/CFS and post-COVID-19 syndrome, with the lack of distinguishing features and the difficulty in diagnosing which is which.

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Sheffield ME and Fibromyalgia Group (inc long COVID)	Guideline	Identification	1.3 [UPDATED] For people with new or ongoing symptoms…	Amend. For people with ongoing symptoms after acute COVID-19, suspect ongoing symptomatic COVID-19/post-COVID-19 syndrome. For people presenting with new symptoms after acute COVID-19 infection, these should be investigated appropriately to ensure other possible causes are eliminated, and particualrly if relevent blood tests were not conducted at an earlier stage. Some patients are reporting that doctors are assuming their symptoms are COVID-related when there may be other other causes which are being missed.
Long Covid Support	Guideline	Identification	1.3 [UPDATED] For people with new or ongoing symptoms…	The ongoing symptomatic SNOMED code (weeks 4-12) was used in 8.2% of patient records, compared with the post covid-19 code (weeks 12+) which was used in 64.3%. It would be interesting to know if all patients coded as ongoing symptomatic then went on to be coded as post covid-19 or whether they all recovered before the 12 week cut off. If not, is there sufficient value in having this separate code, considering its time-limited application vs the time it takes to get a GP appointment presently? The WHO's clinical case definition will include one definition, not two separate syndromes, for those who are ill for at least 8 weeks. Recommend aligning. There needs to be clearer guidance to people on the risk of them still having infectious disease in the ongoing symptomatic stage. Not just being aware of wide ranging and fluctuating symptoms but documenting this to identify patterns and when symptoms worsen, e.g. relative to vaccination, increased activity, diet, stress, menstruation etc.
Long Covid Wales	Guideline	Identification	1.3 [UPDATED] For people with new or ongoing symptoms…	As in 1.1 - Individuals who have been infected with SARS-CoV-2 and who have not developed acute COVID-19, but nonetheless go on to develop Long COVID/post-COVID are now well described, so this possibility should be given for medical practitioners to consider the possibility.
NHSEI - specialised commissioning	Guideline	Identification	1.3 [UPDATED] For people with new or ongoing symptoms…	Consideration of “acute COVID-19” should not be restricted to those with a positive swab or, indeed, those who had acute symptoms (i.e allowing for no swab/swab negative/asymptomatic acute Covid infection.)

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NHSEI - specialised commissioning	Guideline	Identification	1.3 [UPDATED] For people with new or ongoing symptoms…	In the psychology box Prioritise information sharing re physical health status and management plans so that psychological and physical health needs are well integrated
NHSEI - specialised commissioning	Guideline	Identification	1.3 [UPDATED] For people with new or ongoing symptoms…	Agree with time thresholds
Welsh Government	Guideline	Identification	1.4 [UPDATED] For people who are concerned... offer an initial consultation	Links with 1.3
Royal College of General Practitioners	Guideline	Identification	1.4 [UPDATED] For people who are concerned... offer an initial consultation	Can the committee please change the terminology from 'concerned' which implies symptoms may be imagined and not real. We would suggest rephrasing to "for patients who are experiencing new or ongoing symptoms 4 weeks or more after acute COVID-19…" We would also like to highlight that while an in-depth consultation, that can often last up to an hour, between a patient and clinician or skilled health care professional can be very informative about the patients' experience, it is essential that the decision to investigate further should be made together, as part of shared decision making, and not just at the directive of the patient determining what matters to them.
Royal College of Occupational Therapists	Guideline	Identification	1.4 [UPDATED] For people who are concerned... offer an initial consultation	It would be beneficial to give greater clarity on which professionals are best placed to carry out an initial consultation, based on the person's presenting needs and priorities. As well as general practitioners and nurses, this may also be an occupational therapist, physiotherapist or psychologist. As noted in the expert testimony, this consultation should be focused on what matters to the person and what their goals are. It is important to consider however that asking a person to identify and set goals at an initial consultation may be overwhelming for some, and this should be approached sensitively and flexibly. Referral for clinical tests should not unnecessarily delay a person receiving rehabilitation support. Early rehabilitation input can improve outcomes and reduce psychological distress.

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				The preference for face to face or remote input should be identified and granted at the onset. Local evidence indicates that digital poverty, digital literacy and the location of COVID clinics are all barriers to access for some people, and impacting upon inequalities. Inequality to access should be identified and eradicated. We are concerned by the statement in the rationale – 'The panel also agreed that the format of the consultation should be discussed and agreed with the person according to their needs and preferences and local availability of services.' Local service provision should not over-rule a person's preference. The reference to shared decision making throughout the recommendations is welcome. It will be beneficial to clearly link to resources on shared decision making and personalised care throughout the document, to ensure that the principles of shared decision making are fully understood and applied. A useful resource for training in this area is https://www.personalisedcareinstitute.org.uk/ Screening questionnaires should be focused upon function and ability to participate in daily activities, as well as symptoms. Large numbers of people affected by post COVID-19 syndrome experience difficulty completing day to day activities, which impacts upon independence and psychological wellbeing Developing a standardised approach to screening and assessment could help to reduce inequality of experience, and establish nationally comparable data.
UK Doctors Long Covid	Guideline	Identification	1.4 [UPDATED] For people who are concerned... offer an initial consultation	There is a concerning move towards emphasising the potential for shared decision making to 'alleviate anxiety', this could be interpreted as there is no need to do investigations. The expert testimony needs to be more representative of the Long Covid population – not everyone is ready for the same level fo rehabilitation at the at same stage and the military population and those included in the Nuffield rehabilitation programme are very specific populations, not everything can be extrapolated from these expert testimonies and applied to the whole Long Covid population.
Asthma UK and the British	Guideline	Identification	1.4 [UPDATED] For people who are	We welcome the recommendation which states that an initial consultation should be offered to people with new or ongoing symptoms for 4 weeks or more to facilitate shared decision-making. This is vital in helping people with ongoing and post-COVID symptoms to partake

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Lung Foundation			concerned... offer an initial consultation	in decisions about their own care. Insights from our survey in 2020 highlighted that?people with Long?COVID?symptoms are often dismissed by Healthcare Professionals (HCPs), assumed to be?suffering from anxiety, or simply that their HCPs do not know what support to offer them. Conversations between individuals and HCPs can help ensure that what matters most to people with Long COVID symptoms are considered. We believe that the recommendations should be clear in indicating that in-depth consultations should occur in addition to and not instead of clinical tests, which are important in helping to exclude other respiratory conditions for people presenting with Long COVID-related breathlessness.
Long COVID Scotland Action Group	Guideline	Identification	1.4 [UPDATED] For people who are concerned... offer an initial consultation	• Recommend moving the timeframe of “after 4 weeks” What if someone has chest pain and breathing difficulties at 3 weeks?
Long COVID Physio	Guideline	Identification	1.4 [UPDATED] For people who are concerned... offer an initial consultation	Inclusion of the World physiotherapy briefing paper 9 as a resource would add value to this recommendation, whereby the briefing paper directly addresses person-centred care in the context of Long COVID: “Person-centred approaches to Long COVID rehabilitation will require conscious attention to the therapeutic relationship; the relationship between clinician and patient also known as therapeutic or working alliance.59 This important aspect of clinical interaction is a pillar of person-centred rehabilitation, 60,61 which improves clinical outcomes. 62-64 Therapeutic relationships hinge upon clinicians creating space where patients feel safe to openly engage in rehabilitation,65 with meaningful connections established when clinicians acknowledge and believe patients’ lived experiences, actively include them in decision making, and are receptive and responsive to their suggestions, needs and values.65-69 Considering the clinical complexity and uncertainties of Long COVID, functioning therapeutic relationships are critical in maintaining safe rehabilitation approaches, through recognition, validation and inclusion of patient experiences as a means of personalising treatment.” (Page 5 of briefing paper) https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-

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				2021_0.pdf Page 31: The evidence to decision moving away from conducting clinical tests appears to be based on expert testimony rather than evidence of organ damage and pathophysiological impairment of body function or structure. There is evidence that clinical tests are warranted, valuable and directly guiding treatment and medical interventions. The narrative of this evidence to decision is concerning as it appears to favour moving away from medical management, which is unfounded by existing literature. https://bmjopen.bmj.com/content/11/3/e048391 https://pubs.rsna.org/doi/10.1148/radiol.2021210033 https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370(20)30427-2/fulltext http://www.ajnr.org/content/early/2020/10/29/ajnr.A6877 https://www.clinicalmicrobiologyandinfection.com/article/S1198-743X(21)00335-9/fulltext https://onlinelibrary.wiley.com/doi/10.1002/jum.15778 https://link.springer.com/article/10.1007/s00259-021-05528-4
Long Covid SOS	Guideline	Identification	1.4 [UPDATED] For people who are concerned... offer an initial consultation	'Members of the panel agreed that while clinical tests may still be indicated, particularly to identify the presence of other conditions, a conversation can be more reassuring and reduce anxiety by explaining what is known about ongoing COVID-19 and post-COVID-19 syndrome. ' It would be worthwhile to note that when an individual is still experiencing symptoms, clinical tests in the normal range are not always followed up on in Primary Care and patients can be in a healthcare limbo prior to having a consultation focussed on all their long covid symptoms. Agree there is little point in performing diagnostic tests which are unable to find abnormalities e.g. chest X-ray but for some patients with serious persistent symptoms more specialist tests may be indicated. The tests are not determining the underlying cause of the symptoms because little is currently known. Rather than a conversation being determined to be 'more reassuring and reduce anxiety', it is more that people appreciate their experience being acknowledged and wish to understand what is currently known or unknown. Less paternalistic language should be used. In response to

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				"Consider using a screening questionnaire" : Patients complain about having to fill in multiple, frequent questionnaires some of which contain irrelevant or unsuitable questions
Royal College of Paediatrics and Child Health	Guideline	Identification	1.4 [UPDATED] For people who are concerned... offer an initial consultation	Chest pain and breathlessness should be assessed face to face. • Suggest referring instead of to 'people' to 'young people, or 'children and young people' etc, it comes across very adult. • There are concerns that if remote, then clinical signs could be missed, and tests e.g., sit to stand would not be done, or blood tests. • Agree screening questionnaire useful and will aid research and assessment of recovery. CYP groups are not considering the suggested screening questionnaires mentioned, the reviewers are using quality of life, fatigue and wellbeing/mental health combined questionnaires such as the CFS National outcome data and modified ISARIC as per the CLoCK study.
Long Covid Support	Guideline	Identification	1.4 [UPDATED] For people who are concerned... offer an initial consultation	"Expert testimony (Nichol 2021 and Nuffield Health 2021) suggested that some practice is moving away from conducting lots of clinical tests towards a model where discussion is held with the individual to determine what matters to them and what their goals are." This is likely because many standard clinical tests do not detect pathology, but absence of evidence does not mean evidence of absence. "What matters to patients" is treatment to allow sustainable, symptom-free recovery and resumption of activities of daily living, work, education, sport etc. It is vital that patients are given appropriate investigations to rule out pathology, since there is evidence of patients who push for more advanced tests or received them in research studies having serious issues such as brain clots, lung clots or myocarditis detected, even more than one year post infection. An example, a woman with normal D-dimer and CTPA who pushed for a SPECT VQ scan and was found to have multiple micro-clots. She was subsequently diagnosed with antiphospholipid syndrome and is now receiving treatment for this. She works as an AHP in secondary care and paid privately for the scan. For the year up till that point she was told that all tests were normal and was not offered any useful treatment. The emphasis on shared decision making to alleviate anxiety is concerning - this could be interpreted as there being no need to do investigations. Expert testimony is that a conversation may be more beneficial to alleviate

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				anxiety - beneficial according to who? The experts are saying that the patients find it beneficial - has anyone asked the patients if this is their interpretation of the conversation? Where is the evidence that patients agree with this and find a conversation more beneficial than investigations? All patients with ongoing symptoms should be screened for the common problems known to occur following infection and known to cause ongoing symptoms, using a systems-based approach, in particularly assessing cardiorespiratory, autonomic and clottirng -related issues. We are aware that practice is very variable with some GP surgeries still not routinely providing face to face appointments. Someone with Long Covid still experiencing new or ongoing symptoms should be seen in person at least once for a physical examination especially because presentations such as mast cell disorder and dysautonomia can present with multiple symptoms that are impossible to assess remotely; simple tests as documented below can help achieve a diagnosis but need to be done in the office. The Expert Testimony by Elizabeth Whittaker highlights that for children and young people the initial assessment should be completed face to face. Where language barriers exist consider the appropriateness of telephone/video consultations and if they go ahead ensure access to a foreign language/BSL translator. Particular symptoms should automatically trigger a face to face appointment and specific assessments, e.g. rapid heart rate (ECG, Lean test), breathlessness (oxygen saturation levels), rapid onset psychiatric symptoms (review for PANS/PANDAS in both children and adults - Antibiotic treatment may be indicated). Some people may prefer telephone or video consultation or a home visit due to the level of fatigue they are experiencing. Consider signposting to transport services etc. The use of clinical tests purely as a diagnosis of exclusion creates a false narrative that there is no clinically detectable pathology. It should instead be assumed that as yet, the correct clinical tests have not been determined. In fact, it needs to be emphasised that the absence of abnormalities on initial testing does not mean that there is no physical pathology and that the condition is psychological. Psychological diagnoses should only be made when positive features of those are present, not as a diagnosis of exclusion based on negative tests. Complications such as myocarditis and late peripheral

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				pulmonary emboli may not be picked up on Echo or CTPA, and may require cardiac MRI and VQ respectively, for example. 1.5 (pg 33) (Not clarified whether this is an update to the original but it does appear in the LTE doc marked as a consensus recommendation). Consider the appropriateness of the screening questionnaire chosen in relation to the individual's acute COVID experience - some ask about hospitalisation at the very beginning. For non hospitalised patients this is clearly not relevant and gives the impression that their symptoms may not be taken as seriously. Non hospitalised people additionally may need additional screening investigations. Validate new and existing screening tools - would like to see physical, psychological, psychiatric and social aspects all screened together to better understand the interplay and weight on each one. Social factors always get forgotten but have huge impacts on health and wellbeing.
NHSE - specialised commisioning	Guideline	Identification	1.4 [UPDATED] For people who are concerned... offer an initial consultation	If consultations are offered virtually, ensure sufficient technology is in place. If not, in person appointments should be offered to mitigate against digital exclusion. Translation services should be offered if requested or if there is concern regarding adequate communication. Ensure that offers are made to invite an advocate to the consultation, particularly vulnerable patients, patients with underlying cognitive impairment or those suffering with cognitive symptoms as part of their COVID-19 syndrome, and that communication is culturally competent to meet the patient's needs.
NHSE - specialised commisioning	Guideline	Identification	1.4 [UPDATED] For people who are concerned... offer an initial consultation	On the referral at 4 weeks issue consider adding a recommendation to take in to account the trajectory of symptoms when deciding re the appropriate time for referral. If improving trend can consider continuing to monitor within primary care with appropriate advice.

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NHSE - specialised commisioning	Guideline	Identification	1.4 [UPDATED] For people who are concerned... offer an initial consultation	Agree re ongoing symptoms however NEW symptoms such a breathlessness might represent new pathology (eg PE) which could be missed without F2F review and sat monitoring
Welsh Government	Guideline	Identification	1.6 [UPDATED] Some people...may not have the most commonly reported new or ongoing symptoms...	This reflects clinical variation. It is probably worth stating to alert clinicians to think widely.
Royal College of General Practitioners	Guideline	Identification	1.6 [UPDATED] Some people...may not have the most commonly reported new or ongoing symptoms...	Can the committee please check the link as the link provided in the guidance requires a log in and therefore is not accessible to all.
Royal College of Speech and Language Therapists (RCSLT)	Guideline	Identification	1.6 [UPDATED] Some people...may not have the most commonly reported new or ongoing symptoms...	Your COVID Recovery clearly signposts people post-COVID to swallow and voice support and information, yet this isn't mentioned in the NICE guideline. The RCSLT recommends adding these symptoms to the NICE guideline to provide clarity to patients about what to expect after COVID. https://www.yourcovidrecovery.nhs.uk/managing-the-effects/effects-on-your-body/voice-and-swallowing/ The evidence for adding voice problems to the NICE Guideline listed below: The evidence reports voice problems in secondary age children PIMS-TS with including hoarse voice, dysphonia, and speech and language difficulties. (Molteni 2021), (Penner 2021). Findings from the ZOE COVID app study (where patients report their own symptoms) show that having a hoarse voice is a common symptom in adults both by itself and with other symptoms, and that the prevalence also increases with age which suggests that more adults post-COVID experience this than children. It may also be a predictor of long-term symptoms (Sudre et al., 2021). Davis et al (2021) found that 28% overall participants (who were adults) experienced changes in the voice.

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Public Health England	Guideline	Identification	1.6 [UPDATED] Some people...may not have the most commonly reported new or ongoing symptoms...	The rationale for the inclusion of this recommendation is not clear. Appreciate that the panel want to acknowledge that cardiac and respiratory symptoms are less common in CYP but what should the reader do with this information? Should a healthcare professionals look to consider an alternative diagnosis? It seems to create confusion rather than clarity as it is likely to generate the question 'what are the most common symptoms?' which remains unanswered.
UK Doctors Long Covid	Guideline	Identification	1.6 [UPDATED] Some people...may not have the most commonly reported new or ongoing symptoms...	Why are we commenting on symptoms that are less likely to be present in children but not also the symptoms more likely to be present in children, by omitting the latter it implies a degree of dismissiveness of Long Covid in children, particularly because GPs won't know what symptoms to look for. Also given the recognition that we don't have sufficient data in children to fully draw conclusions is there really sufficient data to say these symptoms are less common in children than adults?
Asthma UK and the British Lung Foundation	Guideline	Identification	1.6 [UPDATED] Some people...may not have the most commonly reported new or ongoing symptoms...	We agree with this recommendation.
Public Health Scotland	Guideline	Identification	1.6 [UPDATED] Some people...may not have the most commonly reported new or ongoing symptoms...	Useful to have included the caveats around young people
Long COVID Scotland Action Group	Guideline	Identification	1.6 [UPDATED] Some people...may not have the most commonly reported new or ongoing symptoms...	• The language suggests these symptoms are rare but it should be reiterated that they do occur: when parents and guardians are contacted by test and trace, they are advised to watch out for breathing difficulties etc.

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Long COVID Physio	Guideline	Identification	1.6 [UPDATED] Some people...may not have the most commonly reported new or ongoing symptoms...	Opportunity here to include post-exertional symptom exacerbation as a common symptom, previously outlined in comment number 1 of this section. Page 33: Consensus recommendation re: screening questionnaires. Using screening tools (or PROMS) to identify symptom and disability is good. Consideration is required to the impact of completing PROMS on cognitive fatigue and PESE, therefore careful consideration and selection of appropriate screening tools is required to avoid symptoms exacerbation through assessment. Page 33: Page 34: Preference and values. We do not agree that people living with Long COVID are anxious due to unnessesary or over investigation. People with Long COVID are reporting they may experience uncertainty or anxiety associated with not having symptoms investigated or not having their symptoms believed. Page 34: The term “worse achievement” carries potential unintended consequences of ableism, stigma, prejudice and blame on individual. It may be worth considering the use of the term “reduced functioning” as this can also apply to education work or training. This has already been conceptualised within the international classification of functioning, disability and health and the Episodic Disability Framework. https://www.who.int/standards/classifications/international-classification-of-functioning-disability-and-health https://gh.bmj.com/content/6/9/e007004
Long Covid SOS	Guideline	Identification	1.6 [UPDATED] Some people...may not have the most commonly reported new or ongoing symptoms...	It would be helpful for symptoms more commonly reported in CYP listed. In response to “The panel also noted the expert testimony advising that many people with new or ongoing symptoms after acute COVID-19 were experiencing anxiety caused by unnecessary investigations “:Conversely, having no investigations will also increase anxiety and the sense of being abandoned by the health system
Patient-Led Research Collaborative	Guideline	Identification	1.6 [UPDATED] Some people...may not have the most commonly reported new or ongoing symptoms...	Instead of reporting what symptoms are signs are less commonly reported in children and young people, provide what symptoms and signs are MORE commonly reported. The usefulness of the less commonly reported without the full list of symptoms is unclear.

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Sheffield ME and Fibromyalgia Group (inc long COVID)	Guideline	Identification	1.6 [UPDATED] Some people...may not have the most commonly reported new or ongoing symptoms...	It is critical that all healthcare professionals are fully aware of and understand post-exertional malaise and screen patients for this symptom which will fundamentally affect their management plan.
Royal College of Paediatrics and Child Health	Guideline	Identification	1.6 [UPDATED] Some people...may not have the most commonly reported new or ongoing symptoms...	The reviewer noted that rather than saying these are less common, it would be of more value to comment on the greater breadth of symptoms experienced by CYP, in particular fatigue, headaches, abdominal pain and anosmia. Consider removing shortness of breath and palpitations from this, the reviewer has found 30-40% shortness of breath in their cohort and in published papers, and palpitations are a common finding likely related to associated autonomic dysfunction partly related to deconditioning perhaps.
Long Covid Support	Guideline	Identification	1.6 [UPDATED] Some people...may not have the most commonly reported new or ongoing symptoms...	The comment about symptoms less likely to be present in children is inappropriate in the absence of mention of those symptoms more likely to be present in children - omission of the latter suggests dismissiveness towards long covid in children. People should be asked about new, or exacerbated existing symptoms since COVID-19 infection, in recognition that COVID-19 can worsen/complicate existing conditions. Screening questionnaires should not be a substitute for taking a full personal history that the patient should have the opportunity to review and correct. Reducing investigations based on expert testimony and assumption that these cause distress is not grounded in evidence. If Nicol et al are reducing investigations prior to offering rehabilitation this may reflect the inadequacy of commonly used investigations in detecting potential pathology among Long Covid patients. Patients should be offered appropriate investigations before rehabilitation is offered to rule out risk factors as outlined in the World Physio paper on safe rehabilitation for people with Long Covid. It should be up to the patient whether they want to not have an investigation on the grounds that it may cause distress, patients don't need protecting from investigations, they need to be treated like adults and fully involved in their own healthcare so that they are fully involved in the decision making process. We note that in our experience, patients want

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				investigations, and although they be may be exhausted after a round of investigations, in general they would rather have had them than not. We can point to hundreds of examples where investigations have revealed new pathology leading to a diagnosis of a treatable de-novo condition, or provided an explanation of symptoms. https://world.physio/news/world-physiotherapy-briefing-paper-focuses-safe-rehabilitation-people-living-long-covid. Consider also offering Coverscan rather than standard MRI scans, to scan multiple organs more efficiently and more effectively detect potential pathology.
Long Covid Wales	Guideline	Identification	1.6 [UPDATED] Some people...may not have the most commonly reported new or ongoing symptoms...	It is good to point this out. Clinical diagnosis should be based on the overall totality of presenting symptoms, not concentrate on individual ones, which argues for experienced practitioners in centralised clinics to give expert opinion.
NHSEI - Specialised commissioning	Guideline	Identification	1.6 [UPDATED] Some people...may not have the most commonly reported new or ongoing symptoms...	Screening questionnaires should also be provided in accessible or translated format where applicable.
NHSEI - Specialised commissioning	Guideline	Identification	1.6 [UPDATED] Some people...may not have the most commonly reported new or ongoing symptoms...	I don't think this wording follows NICE style as there is no action. Should it not be "Be aware that some people….".as has been applied to recs elsewhere?
NHSEI - Specialised commissioning	Guideline	Identification	1.6 [UPDATED] Some people...may not have the most commonly reported new or ongoing symptoms...	Re the nature of rehab, I would add a bullet point recommending that a multimodality rehab offer should include access to support with fatigue management, support for disordered breathing pattern and vocational rehab

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NHSEI - Specialised commissioning	Guideline	Identification	1.6 [UPDATED] Some people...may not have the most commonly reported new or ongoing symptoms...	fine
Royal College of General Practitioners	Guideline	Identification	[NEW] In addition to clinical symptoms...	Can the committee please review this statement and consider amending? It is purely based on expert testimony (rather than evidence) and appears to infer that "increased absence or reduced performance in their education, work or training after acute COVID-19" is directly because of their COVID-19 infection. Can the committee please ensure it is clear that post-COVID-19 syndrome is just one differential diagnosis amongst other important diagnoses which should be ruled out, rather than simply attribute this to Post COVID-19 Syndrome? Bereavement, pandemic effects and other clinical diagnoses must be considered as causes.
Royal College of Speech and Language Therapists (RCSLT)	Guideline	Identification	[NEW] In addition to clinical symptoms...	The RCSLT welcomes the addition of occupational health considerations. There is an opportunity for NICE to build on the current workplace guidance on mental health and highlight long-COVID to support identification for non-healthcare workers. It would be helpful to look at links with employer-support from DWP too.
Royal College of Occupational Therapists	Guideline	Identification	[NEW] In addition to clinical symptoms...	Ability to participate in education, work and training are not the only functional indicators that a person may have ongoing symptomatic COVID-19 or post COVID-19 syndrome. They may have reduced ability to complete a wide range of daily activities, and the impact of this may be significant for their independence and psychological wellbeing. This is why it is essential to include measures of function and daily activity within initial screening questionnaires. Reduced ability to participate in work, education and other daily activities may indicate a need for a direct referral to an occupational therapy, vocational rehabilitation or occupational health service.

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Asthma UK and the British Lung Foundation	Guideline	Identification	[NEW] In addition to clinical symptoms...	We agree with this update.
Public Health Scotland	Guideline	Identification	[NEW] In addition to clinical symptoms...	This seems a very useful addition, and links to 'what matters most' to patients.
Long COVID Scotland Action Group	Guideline	Identification	[NEW] In addition to clinical symptoms...	• This should be mentioned earlier in the document.
#MEAction UK	Guideline	Identification	[NEW] In addition to clinical symptoms...	We support the addition of this recommendation, but note that this is common across many illnesses, including ME/CFS, and therefore believe that the recommendation should end by saying "or other related illness."
Long Covid SOS	Guideline	Identification	[NEW] In addition to clinical symptoms...	This is welcomed.
Patient-Led Research Collaborative	Guideline	Identification	[NEW] In addition to clinical symptoms...	Add "ability to care for themselves or others, ability to exercise, ability to socialize, ability to perform enjoyable activities"
Royal College of Paediatrics and Child Health	Guideline	Identification	[NEW] In addition to clinical symptoms...	The reviewer was very pleased to see this here. There was a suggested to add the term cognitive dysfunction here.
Long Covid Support	Guideline	Identification	[NEW] In addition to clinical symptoms...	Interesting but surely this increased absence or reduced performance would come alongside symptoms such as fatigue, brain fog, general malaise. Surely better to indicate that post-COVID-19 syndrome should be considered in anyone with increased presentation at their general practitioner, or increased absence or reduced performance in work or education. Reduced from what? And identified by whom? Previous baseline. Could we consider impaired rather than reduced. This addition is welcomed, But should also include

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				reduced ability in self care or care for others. People with long covid may be unemployed, but providing care for themselves or their family, Care should also be valued including ability to self care particularly for disabled,homeless, etc. Social/sporting/exercise activities are also an important part of mental health, so reduction in these activities should also be considered e.g.if people prioritise work and caring for others, what they may reduce is social activities and exercise.
Long Covid Wales	Guideline	Identification	[NEW] In addition to clinical symptoms...	As in 1.1 & 1.3 - Individuals who have been infected with SARS-CoV-2 and who have not developed acute COVID-19, but nonetheless go on to develop Long COVID/post-COVID are now well described, so this possibility should be given for medical practitioners to consider the possibility.
NHSEI - Specialised commissioning	Guideline	Identification	[NEW] In addition to clinical symptoms...	Where appropriate, patients should be signposted to the appropriate support services, including social prescribers. Crucially, “education, work or training” should not be considered as the only functional impacts of long Covid as this risks excluding those who are unable to work or participate in education, for example individuals with certain disabilities. Functional assessments should be comprehensive, inclusive, and tailored to each patient’s individual circumstances, needs and priorities.
NHSEI - Specialised commissioning	Guideline	Identification	[NEW] In addition to clinical symptoms...	Why is advice on pharmacotherapy in the self management section.? Would it be better to use the term supplements than pharmacological treatments therefore. I don’t think we should suggest that no pharmacotherapy is ever useful (eg we use rate control occasionally, analgesia, migraine treatment etc……..)
NHSEI - Specialised commissioning	Guideline	Identification	[NEW] In addition to clinical symptoms...	agree
Office for the Chief Allied Health Professions	Guideline	Identification	1.7 [UPDATED] Based on the initial consultation, use shared decision making…	The office for the Chief AHP Officer supports this comment but there needs to be acknowledgement of how all service users can be supported with shared decision making including those with a learning disability and neurodiverse individuals.

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(AHP) Officer at NHS England and Improvement				
Royal College of General Practitioners	Guideline	Identification	1.7 [UPDATED] Based on the initial consultation, use shared decision making…	Can the committee please review this statement as it implies that urgent referrals to not require a face-to-face assessment. We would suggest clarifying this statement to this effect. Please consider "Following taking a history and appropriate examination, offer tests and investigations…."
Royal College of Speech and Language Therapists (RCSLT)	Guideline	Identification	1.7 [UPDATED] Based on the initial consultation, use shared decision making…	Evidence shows that many vulnerable populations are at greater risk of getting COVID include adults with learning disabilities, people with dementia and people who had a stroke, all who have speech, language and communication needs. Support must be provided to people with speech, language and communication needs to make informed decisions and to ensure equity of access to information and support. Establishing each person's communication preferences and providing clear and accessible information is key and should be clearly highlighted in the guideline.
Public Health England	Guideline	Identification	1.7 [UPDATED] Based on the initial consultation, use shared decision making…	Note, the comment below relates to this recommendation: Support access to assessment and care for people with new or ongoing symptoms after acute COVID 19, particularly for those in underserved or vulnerable groups who may have difficulty accessing services, for example by: Comment: It would be helpful to clarify the recommendation on Page 38 about wider awareness raising, and to add some caveats about this. Whilst it is certainly important to provide people with advice on who they should contact / where they can access support if they are experiencing symptoms of Long COVID, any awareness raising about the condition itself needs to be approached very carefully. Given how broad the potential symptoms are, and the lack of ability to accurately predict who might be likely to suffer from them, there is a real risk that broad communication about the likelihood / symptoms / severity of the condition will increase attribution of symptoms to Long COVID (even if these are unrelated), will increase negative expectations about Long COVID, and

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				will potentially have an adverse impact on health outcomes. Any broader public information should therefore focus on raising awareness of the support available, rather than the severity / impact of the condition. It would be useful to update the recommendation to reflect this. [PHE Behavioural Insights team comment]
UK Doctors Long Covid	Guideline	Identification	1.7 [UPDATED] Based on the initial consultation, use shared decision making…	Shared decision making is important, but for this to occur properly the initial consultation with the clinician/GP should be in person with a FULL clinical examination. Thereafter the decision can be made to continue remotely or in person, everyone should have at least a full in person, clinical examination/assessment.
Asthma UK and the British Lung Foundation	Guideline	Identification	1.7 [UPDATED] Based on the initial consultation, use shared decision making…	We agree with this update but feel the recommendation should be clear in indicating that in-depth consultations should occur in addition to clinical tests, which are important in helping to exclude other respiratory conditions for people presenting with suspected Long COVID-related breathlessness.
Polymyalgia Rheumatica and Giant Cell Arteritis Scotland (PMR-GCA Scotland)	Guideline	Identification	1.7 [UPDATED] Based on the initial consultation, use shared decision making…	True sharing of the decisions to be taken must ensure that the patient has adequate knowledge of the available options and consequences. Without this and without an awareness of the patient's values and preferences there is likely to be dissatisfaction with the choices made and perhaps a lack of adherence to suggested actions.
Long COVID Scotland Action Group	Guideline	Identification	1.7 [UPDATED] Based on the initial consultation, use shared decision making…	• Evidence recommends that anyone with ongoing symptoms of a novel disease needs to be assessed, albeit to different degrees.
Long Covid SOS	Guideline	Identification	1.7 [UPDATED] Based on the initial consultation, use shared decision making…	“There was evidence supporting further assessment in person after initial assessment”: The suggestion that one initial assessment could ever have been considered adequate is worrying

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Royal College of Paediatrics and Child Health	Guideline	Identification	1.7 [UPDATED] Based on the initial consultation, use shared decision making…	The reviewer was not very comfortable with children only being assessed remotely if they are identified to be missing education, this is a safeguarding concern. There are concerns about risk if not offering all new presentation of post COVID-19 syndrome a face-to-face examination and assessment, especially if symptoms significant enough to result in loss of education/work. The reviewer supports the next two recommendation on equality page 38.
Long Covid Support	Guideline	Identification	1.7 [UPDATED] Based on the initial consultation, use shared decision making…	Clear concise guidelines should be made available for patients as to what they should expect from 'shared decision making'. Shared decision making in this context is concerning. We would much rather that further assessment is always offered and people have the right to withhold consent once the health professional shares their concerns and highlights the benefits of further assessment. For shared decision making to happen properly the initial consultation should be face to face with a full clinical examination. Follow up may be remote as appropriate Not just acknowledge symptoms but validate someone's experience. This is vital for shared decision making to be trusted - especially for first wavers who may have had negative healthcare experiences
Long Covid Wales	Guideline	Identification	1.7 [UPDATED] Based on the initial consultation, use shared decision making…	Medical practitioners should have a low threshold for onward referral of symptoms and signs that may indicate serious actionable pathology, given that this is a new disease and it cannot be assumed that the usual indicators apply, e.g. headache with cerebral venous thrombosis.
NHSEI - Specialised commissioning	Guideline	Identification	1.7 [UPDATED] Based on the initial consultation, use shared decision making…	If consultations are offered virtually, ensure sufficient technology is in place. If not, in person appointments should be offered to mitigate against digital exclusion. Translation services should be offered if requested or if there is concern regarding adequate communication. Ensure that offers are made to invite an advocate to the consultation, particularly vulnerable patients, patients with underlying cognitive impairment or those suffering with cognitive

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				symptoms as part of their COVID-19 syndrome and that communication is culturally competent to meet the patient's needs.
NHSEI - Specialised commissioning	Guideline	Identification	1.7 [UPDATED] Based on the initial consultation, use shared decision making…	This is not flagged as updated in the guideline.
NHSEI - Specialised commissioning	Guideline	Identification	1.7 [UPDATED] Based on the initial consultation, use shared decision making…	Re the service organisation: I would add after "carrying out further tests and investigations and define a personalised management approach and referral for further support / rehabilitation / psychology support where appropriate
NHSEI - Specialised commissioning	Guideline	Identification	1.7 [UPDATED] Based on the initial consultation, use shared decision making…	fine
Welsh Government	Guideline	Identification	1.10 [UPDATED] A healthcare professional in secondary care…	This is nebulous. Virtual or physical consultation? What level of clinician? Reference to Primary Care actions should be made.
Royal College of General Practitioners	Guideline	Identification	1.10 [UPDATED] A healthcare professional in secondary care…	Can the committee review this recommendation and consider adding, based on clinical need using shared decision making? Whilst we understand the value of this recommendation within the guideline, we believe that it may not be feasibly undertaken in the current healthcare climate. Many of our secondary care colleagues are already vastly overstretched with their current clinics and patient lists and it may be unrealistic to expect them to have the time to follow up with all patients six weeks after their discharge.
Royal College of Occupational Therapists	Guideline	Identification	1.10 [UPDATED] A healthcare professional in secondary care…	It would be beneficial to give greater clarity on which health professionals are best suited to offer this consultation, based on the person's needs, preferences and goals. As well as medical and nursing staff, this may also be an occupational therapist, physiotherapist or psychologist, for example. Local evidence indicates that services are not currently

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				reaching BME communities. A considered and person-centred approach is needed to ensure that people from diverse communities are reached appropriately and effectively, and are receiving an equitable level of support.
Asthma UK and the British Lung Foundation	Guideline	Identification	1.10 [UPDATED] A healthcare professional in secondary care…	We are happy with this recommendation.
Long COVID Scotland Action Group	Guideline	Identification	1.10 [UPDATED] A healthcare professional in secondary care…	• People who haven't been in hospital also require secondary care. • What type of secondary care professional? Long Covid is multi-system.
Long Covid SOS	Guideline	Identification	1.10 [UPDATED] A healthcare professional in secondary care…	Couldn't PHE (or equivalent) automatically send a digital follow-up email/text to everyone or their GP 6 weeks after a positive test? To ensure the prevalence accuracy is improved, rather than 'consider' with those who self-manage, outreach to underserved communities should be improved to ensure recognition of cases within all groups.
SIGN Council Scottish Intercollegiate Guidelines Network	Guideline	Identification	1.10 [UPDATED] A healthcare professional in secondary care…	Who should this healthcare professional be? Should there be a designated service (potential service development opportunity) or shall the discharging Unit just offer a review appointment in six weeks in the respiratory service?
Sheffield ME and Fibromyalgia Group (inc long COVID)	Guideline	Identification	1.10 [UPDATED] A healthcare professional in secondary care…	Amend: A healthcare professional in secondary care should offer a follow-up consultation afetr 2 weeks and again after 6 weeks ..... We are concerned that because longCOVID can be so fluctuating that a single follow-up will not provide a real picture and for those who have to get to grips with living with a chronic condition, getting good support, especially for vulnerable groups, is a huge challenge to navigate.
Royal College of Paediatrics	Guideline	Identification	1.10 [UPDATED] A healthcare professional in secondary care…	Should consider offering. Could be remote.

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and Child Health				
Long Covid Support	Guideline	Identification	1.10 [UPDATED] A healthcare professional in secondary care…	Pg. 38 1.9 Why is follow-up by primary care only a consideration and not a standard offering. Especially considering people in vulnerable and high-risk groups are less likely to seek out health care. Why does it have to be a health professional in secondary care and why just with hospitalised people when we know post-Covid-19 syndrome affects more groups? Which specific health professionals?
Long Covid Wales	Guideline	Identification	1.10 [UPDATED] A healthcare professional in secondary care…	Yes, but a similar approach should apply in primary care to avoid missing individuals who have "sweated it out" in the community, but who may have been worthy of admission.
British Thoracic Society	Guideline	Identification	1.10 [UPDATED] A healthcare professional in secondary care…	Suggest provide a window of 6-12 weeks as many patients make a full recovery with self – management within the first 12 weeks – this approach maximises the use of the consultation and any onward referrals. Patients at discharge should receive the self-management advice recommended in section 8.
NHSEI - Specialised commissioning	Guideline	Identification	1.10 [UPDATED] A healthcare professional in secondary care…	If consultations are offered virtually, ensure sufficient technology is in place. If not, in person appointments should be offered to mitigate against digital exclusion. Translation services should be offered if requested or if there is concern regarding adequate communication. Ensure that offers are made to invite an advocate to the consultation, particularly vulnerable patients, patients with underlying cognitive impairment or those suffering with cognitive symptoms as part of their COVID-19 syndrome and that communication is culturally competent to meet the patient's needs.

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NHSEI - Specialised commissioning	Guideline	Identification	1.10 [UPDATED] A healthcare professional in secondary care…	Re the sharing knowledge and skills sharing I would add fatigue management and management of palpitations/ autonomic symptoms. Re common symptoms section 12 I don't think weight loss is common and would worry about normalising that as a long covid symptom. Menstrual disturbance is very common and I think should be included. Ive included a relevant reference – paper by Athena Akrani, https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370(21)00299-6/fulltext. A.5 Reproductive/Genitourinary/Endocrine symptoms Total of 2979 respondents reported that the question "If applicable, do you have periods/a menstrual cycle" applied to them by responding either Yes, No - Post-Menopausal, or No - Other. Of the 1792 respondents who reported having periods/a menstrual cycle, 36.1% (95% confidence interval 33.8% to 38.3%) reported experiencing menstrual/period issues. For this group, these issues included abnormally irregular periods (26.1%, 24.0% to 28.2%, Figure 2b, Supplemental Table S7) and abnormally heavy periods/clotting (19.7%, 18.0% to 21.6%). Of the 1123 cis women respondents over 49, 4.5% (3.46% to 5.85%) experienced post-menopausal bleeding/spotting. Of the 938 cis women respondents in their 40s, 3.0% (2.0% to 4.3%) experienced early menopause.
NHSEI - Specialised commissioning	Guideline	Identification	1.10 [UPDATED] A healthcare professional in secondary care…	Many will be still symptomatic at 6 weeks. The emphasis at this time point should be on a brief conact (eg telephone which would serve two purposes: 1. To pick up red flag issues (the few) 2. To reassure re ongoing symptoms at this point (the many)

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Long COVID Scotland Action Group	Guideline	Assessment	2.6. [SUPPORTING REMARK ADDED] ...For more advice on supporting adults to make their own decisions if they may lack mental capacity...	• The guidance needs to be linked within this document. • There should be a note about stigma here – patients use advocates for many reasons and it shouldn't be assumed it is a mental health issue; we need to resist the historical stigma of chronic illness being psychologised.
Long Covid SOS	Guideline	Assessment	2.6. [SUPPORTING REMARK ADDED] ...For more advice on supporting adults to make their own decisions if they may lack mental capacity...	When taking a history of other conditions, we would recommend that it is questioned if these have worsened following COVID-19. Evidence exists that LC can worsen chronic conditions such as diabetes It may be worth linking back the cognitive symptoms to the new section on work related issues.
Royal College of Paediatrics and Child Health	Guideline	Assessment	2.6. [SUPPORTING REMARK ADDED] ...For more advice on supporting adults to make their own decisions if they may lack mental capacity...	Page 39, under consensus recommendation, add social e.g., biopsychosocial and family history, as well as premorbid medical or psychological problems. Also add history of other medical or psychological health conditions. Suggest instead of functional abilities to assess the effect on function such as ability to attend school, college or work, or activities, socialisation etc. Again, turn work and education around p40. Top of page 40 also applied to children whose parents may well be involved in the consultation- this part sounds very adult. Remove box at end as it is about dementia in older people. Suggest advise validated screening tests or onward referral e.g., to psychology if you are going to advise this at the top of p42.
Long Covid Support	Guideline	Assessment	2.6. [SUPPORTING REMARK ADDED] ...For more advice on supporting adults to make	Patients may need support to understand and remember what is said in appointments, and to advocate. Having a family member or carer present for all is a helpful strategy for those with fatigue and brain fog. Remember that capacity is assessed for each decision. People may have capacity to make some decisions but struggle with more complex decisions.

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			their own decisions if they may lack mental capacity...	Allowing time, providing information in a range of formats and reviewing knowledge and understanding. An 'unwise' decision does not automatically mean someone lacks capacity.
NHSEI - Specialised commissioning	Guideline	Assessment	2.6. [SUPPORTING REMARK ADDED] ...For more advice on supporting adults to make their own decisions if they may lack mental capacity...	Fine on this point
Welsh Government	Guideline	Investigations Referral	3.1 and 3.2 [UPDATED] Offer tests and investigations tailored to people's signs and symptoms…	Agree - In line with standard practice.
Royal College of Speech and Language Therapists (RCSLT)	Guideline	Investigations Referral	3.1 and 3.2 [UPDATED] Offer tests and investigations tailored to people's signs and symptoms…	A loss of interest in eating and drinking may indicate dysphagia. It is important to screen for this and rule this out, to prevent deteriorating health outcomes. Whilst NICE recognises that eating and drinking difficulties may be due to frailty, we know that people post-COVID can also experience dysphagia. Patients who have been intubated or had a tracheostomy have an ongoing risk of eating, drinking and swallowing difficulties. Evidence indicates the prevalence of swallowing difficulties both in people who were acutely ill with COVID requiring tracheostomy/ventilation - for example, Dawson et al. (2020) cohort study showed 28% of patients admitted to acute care with COVID-19 required a swallow assessment. Furthermore, those who were not hospitalized or acutely still report a difficulty with swallowing or 'lump in the throat' (e.g. almost a third of those reported this, 7 months on from COVID-19 onset in Davis et al., 2021). Fatigue, chronic fatigue and muscular fatigue are also closely associated with swallowing problems (See e.g. Soloman, 2012). As fatigue

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				is a well documented symptom of Long COVID, swallow assessment should always be considered. It should be noted that patients often describe this as a 'lump in the throat', whilst, as a profession, we recognise this Long COVID symptom as a post-COVID swallowing condition requiring treatment. On a related note, voice should be evaluated and treatment for voice difficulties and / or swallowing exercise rehabilitation programmes are needed. These were not highlighted in any of the expert testimonies detailing rehabilitation programmes for patients with ongoing COVID-19 signs and symptoms. The RCSLT recommends referencing these research studies. 1. Regan et al 2021 Post?extubation dysphagia and dysphonia amongst adults with COVID?19 in the Republic of Ireland: A prospective multi?site observational cohort study https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8444742/ 2. Brodksy et al 2020 The long term effects of COVID 19 on Dysphagia evaluation and Treatment https://www.archives-pmr.org/article/S0003-9993(20)30295-1/fulltext
Royal College of Occupational Therapists	Guideline	Investigations Referral	3.1 and 3.2 [UPDATED] Offer tests and investigations tailored to people's signs and symptoms…	We are supportive of the expert testimony advocating a move from lots of clinical tests towards a model which prioritises discussion with the person and a focus upon what matters to them and their personal goals. Referral for clinical tests should not unnecessarily delay a person receiving rehabilitation. Early rehabilitation input can improve outcomes and reduce psychological distress.
UK Doctors Long Covid	Guideline	Investigations Referral	3.1 and 3.2 [UPDATED] Offer tests and investigations tailored to people's signs and symptoms…	If referring patients for exercise tests please clarify the criteria for determining who is suitable/not suitable for such a test.
Asthma UK and the British Lung Foundation	Guideline	Investigations Referral	3.1 and 3.2 [UPDATED] Offer tests and investigations tailored to	We agree that tests must be tailored to people's signs and symptoms to rule out acute or life-threatening complications. As well as to find out if symptoms are likely to be caused by ongoing symptomatic COVID19, post-COVID19 syndrome or could be a new, unrelated diagnosis. For people with Long COVID-related breathlessness, we believe that lung

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			people's signs and symptoms…	function tests such as spirometry should be included as part of these investigations, as standard to help better identify and diagnose the root cause of the individual's breathlessness and rule out any other potential conditions. Guidance is likely to be needed to assist with identifying those who would benefit from other lung function tests and signposting to advice on carrying these out safely, in line with the Primary Care Respiratory Society spirometry guidance https://www.pcrs-uk.org/news/new-update-spirometry-guidance
PoTS UK	Guideline	Investigations Referral	3.1 and 3.2 [UPDATED] Offer tests and investigations tailored to people's signs and symptoms…	We (the charity PoTS UK) are delighted that a stand test for Postural Tachycardia Syndrome remains a guideline recommendation for those experiencing palpitations and dizziness. We know that timely diagnosis and management of this under-diagnosed condition has significant implications for quality of life and overall prognosis. The condition is significantly under-diagnosed, particularly so in minority and lower SES groups, and we are hopeful that this guideline recommendation will enable more equitable access therefore to diagnosis and treatment. We would advocate than in addition to these symptoms that also brain fog, light-headedness, fatigue, blood pooling, peripheral numbness and other indications of autonomic nervous system dysregulation (such as temperature regulation difficulties) might also trigger the recommendation for a stand test to be routinely undertaken.
Long COVID Scotland Action Group	Guideline	Investigations Referral	3.1 and 3.2 [UPDATED] Offer tests and investigations tailored to people's signs and symptoms…	• This is good but should include the need for some standard tests for hidden conditions such as myocarditis and clots. • It's important to be comprehensive – consider the historical biases. • It would be helpful to include examples here that capture the weight of the condition – people need more than a blood count and pulse oximetry.
#MEAction UK	Guideline	Investigations Referral	3.1 and 3.2 [UPDATED] Offer tests and investigations tailored to	By stating that "new symptoms [...] could be a new, unrelated diagnosis" this explicitly excludes diseases such as ME/CFS that can be triggered by COVID-19. The committee shouldn't make a judgement that new symptoms are unrelated to COVID-19, but

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			people's signs and symptoms…	acknowledge that our evidence base is limited, and therefore simply state "or another diagnosis". This comment applies to 3.3 as well.
Faculty of Intensive Care Medicine	Guideline	Investigations Referral	3.1 and 3.2 [UPDATED] Offer tests and investigations tailored to people's signs and symptoms…	The definition of Post-COVID-19 syndrome is "signs and symptoms that develop during or following an infection consistent with COVID-19, continue for more than 12 weeks, and are not explained by an alternative diagnosis". It is not clear whether an "alternative diagnosis" might include the so-called 'post-intensive care syndrome (PICS)'. PICS does not have a strict definition (as far as I know), but encompasses the collection of symptoms (physical, psychological, emotional) that persist beyond hospitalisation for a critical illness. There is a large overlap between Common Symptoms of post-COVID-19 syndrome (section 12) and symptoms of PICS. Including PICS as an "alternative diagnosis" in the definition of 'post-COVID-19 syndrome', thereby excluding patients recovering after a critical illness from being diagnosed with 'post-COVID-19 syndrome', would be undesirable, as it could potentially exclude these patients from the measures described in this NICE guidance. The definition therefore requires clarification that PICS is not included as an "alternative diagnosis" excluding patients from the 'post-COVID-19 syndrome' definition.
Long Covid SOS	Guideline	Investigations Referral	3.1 and 3.2 [UPDATED] Offer tests and investigations tailored to people's signs and symptoms…	We would welcome acknowledgement of neurological testing for things like dysaunomia/POTS as well as other common neurological LC symptoms. We note that the test for POTS is described on pg 46.
Patient-Led Research Collaborative	Guideline	Investigations Referral	3.1 and 3.2 [UPDATED] Offer tests and investigations tailored to people's signs and symptoms…	Due to it being potentially dangerous for people who go through with an exercise tolerance test, recommend providing specific guidance on how to determine who can take one.
Royal College of Paediatrics	Guideline	Investigations Referral	3.1 and 3.2 [UPDATED] Offer tests and	Multisystem Inflammatory Syndrome (in children). Suggest using current common terminology for the UK and elsewhere i.e., Paediatric Inflammatory Multisystem Syndrome

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and Child Health			investigations tailored to people's signs and symptoms…	– Temporally Associated with SARS-CoV-2 (PIMS-TS) or Multisystem Inflammatory Syndrome in Children (MIS-C). All children with fever for more than 5 days should be clinically assessed. • Children and young people instead of people. • Bottom of page 42 mentions ECG and echo to exclude myocarditis where chest pain a symptom. • Top of page 43 - extreme care needed here as there are many YP whose GPs/paediatricians have been sending to numerous ologists. Suggest adding sit to stand test, signs of severe lung disease doesn't sound clinically appropriate in children, prefer shortness of breath, palpitations, chest pain, covid toes and fingers to exclude inflammatory conditions, severe headaches may need MRI.
Long Covid Support	Guideline	Investigations Referral	3.1 and 3.2 [UPDATED] Offer tests and investigations tailored to people's signs and symptoms…	Are certain tests most commonly referred to in the evidence because these are the tests most commonly used by historical default? As this is a new disease course should consideration be given to the fact that research may indicate other tests to be more suitable? People need to be aware of all of the potential symptoms and highlight where pre-Covid symptoms have worsened to get a complete picture. …"exercise tolerance tests (if safe and appropriate for the person)" what guidance is given as to how to determine whether exercise tolerance tests are safe and appropriate for that person, and what is in place to gather information on post-exertional symptom exacerbation that may occur in the days following such tests? World Physio briefing paper is useful for this. "If another diagnosis unrelated to COVID-19 is suspected, offer investigations and referral in line with relevant national or local guidance" Consideration should be given to the potential need to 'dual code' patients, to be able to track prevalence of existing and later conditions that may be associated with Long Covid. How are you defining severe hypoexemia or oxygen desaturation? Many people regularly drop to the low 90s and 80s and have not had this investigated. Give advice and guidance on how to monitor this and when to highlight with healthcare team - e.g. duration of drop, figures, comparison to pre-Covid-19 infection if known (e.g. for those with COPD). Can you include some key symptoms of multisystem inflammatory disorder or link in here. In general further guidance could be given about

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				which health professionals are best suited to assess particular aspects of someone's post-Covid-19 experience (as an example, mobility is best addressed by physiotherapists, life and activities by an occupational therapist, cognition by Occupational Therapy or Psychology). Consider also the role of occupational therapists in supporting people with a better life balance which can lift mood. Talking therapies should not be focused on the denial of real symptoms and experiences. How can we be sure other diagnoses are unrelated and not precipitated by Covid-19, e.g. ME/CFS, organ damage, auto immune conditions, POTS, etc. The problem with going by local guidance/service availability is in variability of approach. We have huge concerns about children, particularly in Scotland - as outlined in the Expert Testimonial by Dr Mairi Stark, being subsumed by ME/CFS clinics especially with the controversy surrounding the delay to the publication of the ME/CFS NICE guidance and the ongoing delivery of GET and CBT which risk harm to adults and children.
Long Covid Wales	Guideline	Investigations Referral	3.1 and 3.2 [UPDATED] Offer tests and investigations tailored to people's signs and symptoms…	Yes, but as in 1.7 - Medical practitioners should have a low threshold for onward referral of symptoms and signs that may indicate serious actionable pathology, given that this is a new disease and it cannot be assumed that the usual indicators apply, e.g. headache with cerebral venous thrombosis.
British Thoracic Society	Guideline	Investigations Referral	3.1 and 3.2 [UPDATED] Offer tests and investigations tailored to people's signs and symptoms…	*'postural symptoms are common' – which objective data supports this?
Aneurin Bevan University Health board	Guideline	Investigations Referral	3.4 [UPDATED] Offer blood tests if clinically indicated…	We could maybe separate out blood tests into children and adults. For children I think a coeliac screen would be very helpful as we are seeing children with fatigue a lot and this would be helpful if done at time of referral in primary care

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Welsh Government	Guideline	Investigations Referral	3.4 [UPDATED] Offer blood tests if clinically indicated…	These points are linked. There needs to be a balance between appropriate and proportionate investigation and wider pressures / influences that may be prevalent.
Royal College of General Practitioners	Guideline	Investigations Referral	3.4 [UPDATED] Offer blood tests if clinically indicated…	Can the committee please alter the emphasis on this recommendation to ensure the clinically indicated part is most prominent? Please consider rewording as: "If clinically indicated, offer appropriate blood tests and other appropriate investigations based on clinical symptoms". Whilst investigation may include blood tests there is likely to be a need for other investigations such as ECG, Xrays and appropriate diagnostic tests to determine the cause of symptoms. Currently the consensus recommendation limits investigations to blood tests. Clinicians know what tests to do as this is part of their generic training and adding a list of specific tests, without evidence, based upon consensus is not helpful to primary care. A wider and more general statement would be more helpful for primary care which will then prevent over investigation and ensure appropriate investigations are performed.
UK Doctors Long Covid	Guideline	Investigations Referral	3.4 [UPDATED] Offer blood tests if clinically indicated…	D-dimer should be included if respiratory symptoms/chest pain and being seen in secondary care. Would it not be sensible for a few baseline blood investigations to be arranged for all patients who are willing to have them given the association of COVID with diabetes, thyroid disorders and renal impairment? Also for identifying vitamin D deficiency and anaemia, which can easily be managed in primary care. The expert testimonies that are cited as evidence as to the limited value for investigations should not be used for this purpose: Patients in the Nichol testimony were heavily investigated and they highlighted limited value of SOME investigations though it is not clear which investigations were ordered for which symptoms and signs. Indeed 75% of patients were offered 2 weeks of inpatient investigation and treatment, that this might not be required does not mean that NO investigations are required. Nichol specifically states that exercise testing is of value though not widely available. The Nuffield evidence is based on a service that is founded on a 'no investigation' rehab model. They report outcomes of fewer than 10% of the patients who

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				were referred. We know that patients are excluded if they are not well enough for the exercise aspect of the rehab (we are aware of several individuals who have been referred but after the first interview been informed they are not well enough to take part). This is not addressed in their expert testimony, but has significant implications in regard to drawing any conclusions of relevance in relation to investigations of people with Long Covid, other than for the small proportion of people who are well enough to take part in an active rehab programme. Presumably patients were referred on the basis that they were 'fit for rehab', and therefore did not require ongoing investigations. This service in no way looked to assess the value of investigations.
Asthma UK and the British Lung Foundation	Guideline	Investigations Referral	3.4 [UPDATED] Offer blood tests if clinically indicated…	We have no comments on this recommendation.
Long COVID Scotland Action Group	Guideline	Investigations Referral	3.4 [UPDATED] Offer blood tests if clinically indicated…	• Blood tests are always clinically indicated in ongoing illness of this type. • It's important to be more comprehensive to include troponin and D-dimer, given the risks of heart inflammation and clots. There's plenty of evidence to support this – concerned these have been left out due to them being considered hospital tests – but we can't force Long Covid into the primary care box; it doesn't fit and could do harm.
Long Covid SOS	Guideline	Investigations Referral	3.4 [UPDATED] Offer blood tests if clinically indicated…	With regards to moving away from diagnostic tests, we have some concern that this may result in patients being denied diagnostic tests which may help identify the cause of their symptoms. However, we would welcome this steer away from a specified list of tests being necessary for the initial assessment, as reports have been made of referrals being declined due to a series of recent blood tests not being taken.
Patient-Led Research Collaborative	Guideline	Investigations Referral	3.4 [UPDATED] Offer blood tests if clinically indicated…	Antiphospholipid panel and lipid panel are also recommended, as both have come back abnormal even in non-hospitalized patients.

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Royal College of Paediatrics and Child Health	Guideline	Investigations Referral	3.4 [UPDATED] Offer blood tests if clinically indicated…	Unsure of the validity or utility of this specific list of suggested investigations. Would suggest not including a list, instead investigations as appropriate for potential differential diagnoses. • "Offer blood tests if clinically indicated and guided by symptoms, which may include a full blood count, kidney and liver function tests, C?reactive protein, ferritin, B?type natriuretic peptide (BNP), HbA1c, and thyroid function tests" suggest change to FBC, kidney liver and bone , blood film, coeliac screen, CK, ferritin, thyroid function tests and urine dip. • HBA1C is not an appropriate text for newly diagnosed diabetes, P43. • Bottom of page 43, the reviewer is concerned that is pathology not excluded serious conditions may be missed.
Long Covid Support	Guideline	Investigations Referral	3.4 [UPDATED] Offer blood tests if clinically indicated…	It makes sense for a few baseline blood investigations to be offered to all patients given the association of Covid with diabetes, thyroid problems and renal impairment. Vitamin D deficiency and anaemia should be screened for as symptoms can overlap and they can be easily managed. D-dimer should be performed in those with respiratory symptoms/chest pain in secondary care. Given the increasing evidence of hypercoagulability as the endpoint of the pathophysiology in Long Covid, an argument could be made for conducting a D-dimer in all patients. Be aware that a normal D-dimer may not exclude thromboembolism, however. Consider the possibility that the ranges defined as 'normal' in blood and other tests may not be appropriate to detect issues with Long Covid. Is there scope to test for autoantibodies or hypercoagulability? Antiphospholipid panel and lipid panel are also recommended, as both have come back abnormal even in non-hospitalized patients. State explicitly that normal blood tests do not mean absence of pathology and certainly do not equate to a psychological diagnosis. Is there a pattern whereby a number of tests coming back at slightly out of range should be investigated? And also what are optimal ranges for improved recovery - e.g. someone with low normal ferritin may still benefit from supplementation if it will improve symptoms. The expert testimonies quoted from the Nichol testimony and the Nuffield programme are not generalisable to the general long covid population. The former had a heavy bias towards inpatient investigation and treatment- this

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				does not equate to saying that no investigation is required. The latter programme is based on a progressive overload pattern, which is inappropriate for the majority of patients with long covid. There is plenty of anecdotal evidence of high dropout from the programme as patients with PEM and dysautonomia are unable to complete it (the stated intention is to screen such patients out, however in practice this is not happening uniformly and inappropriate patients are being accepted onto the programme). Healthcare professionals should use caution when conducting exercise capacity testing in some patients, especially those with post-exertional malaise (i.e., the worsening of symptoms following even minor physical or mental exertion, with symptoms typically worsening 12 to 48 hours after activity and lasting for days or even weeks). For these patients and others who may not have the stamina for extended or lengthy assessments, modifications in the testing plan may also be needed. Exercise capacity tests should be scheduled for a dedicated follow-up appointment so that patients can prepare additional home supports. Ensuring that the testing circumstances best support the patient to perform maximally and then documenting this performance can create an objective reliable record of functional status that may be needed for assessment for other services or disability.
Long Covid Wales	Guideline	Investigations Referral	3.4 [UPDATED] Offer blood tests if clinically indicated…	Yes, but it important that such tests be available. In NHS Wales many tests, e.g. for troponin, cannot be ordered in primary care.
British Thoracic Society	Guideline	Investigations Referral	3.4 [UPDATED] Offer blood tests if clinically indicated…	Suggest adding in Vitamin D to the list (body pain is common as is vit D deficiency and easily treated)
NHSEI - specialised commissioning	Guideline	Investigations Referral	3.4 [UPDATED] Offer blood tests if clinically indicated…	3.1 and 3.2 [UPDATED] Offer tests and investigations tailored to people's signs and symptoms… Is this rec 3.1 or 3.2?

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				I can only find 1 recommendation (which is not flagged as updated in the guideline) in Section 6 reading "Offer tests and investigations tailored to people's signs and symptoms to rule out acute or life-threatening complications and find out if symptoms are likely to be caused by ongoing symptomatic COVID-19, post-COVID-19 syndrome or could be a new, unrelated diagnosis." This recommendation is neither new or updated. What and where is the second recommendation? Stakeholders can't comment on this if they can't find it.
NHSEI - specialised commissioning	Guideline	Investigations Referral	3.4 [UPDATED] Offer blood tests if clinically indicated…	3.1 and 3.2 [UPDATED] Offer tests and investigations tailored to people's signs and symptoms… The symptoms of Long Covid are disparate and non-specific. As such, consideration should be given to a Long Covid diagnosis even if not offered by the patient either as a self-diagnosis or in reference to previous acute COVID-19 infection. Similarly, a Long Covid diagnosis should not be made before ruling out other pathologies that may present in a similar way, for example angina, cancer, new onset diabetes and depression. This is stressed because many of these pathologies are known to disproportionately impact those from groups affected by health inequalities, for example patients from more deprived backgrounds and inclusion health groups. If patients have "self-diagnosed" Long Covid, healthcare professionals should respect this (there are, after all, no strict diagnostic criteria) but should feel able and confident to explain to patients that it is important to consider alternative diagnoses. Failure to do so risks exacerbating existing health inequalities, for example in early cancer diagnosis and early COPD diagnosis.
NHSEI - specialised commissioning	Guideline	Investigations Referral	3.4 [UPDATED] Offer blood tests if clinically indicated…	As above

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NHSEI - specialised commissioning	Guideline	Investigations Referral	3.4 [UPDATED] Offer blood tests if clinically indicated…	3.1 and 3.2 [UPDATED] Offer tests and investigations tailored to people's signs and symptoms… in relation to assessment in general the words 'holistic' and 'examination' can have broad interpretation. Post covid some hard physical sequelae occur such as lung fibrosis, myocarditis, clotting abnormalities – with a loose interpretation of 'holistic review' theses can be missed. Tests are important – full lung function tests, including gas transfer – HRCT if symptoms or PFTs indicate, blood tests (eg FBC, U&Es clotting, LFTS, BNP) – in those deemed to require full assessment after 12 weeks Test are needed not just to rule out 'life threatening issues' but also to pick up important pathology that might not be immediately life threatening Given that breathlessness is very common (without underling measurable physiological abnormality) abnormalities such as lung fibrosis can be missed without tests. We may not yet have the evidence to be precisely prescriptive on who requires HRCT for example but a phrase here to add emphasis would be useful.
Welsh Government	Guideline	Investigations Referral	[NEW] Consider supported self-monitoring at home...	Agree – last line may need more emphasis.
Royal College of Occupational Therapists	Guideline	Investigations Referral	[NEW] Consider supported self-monitoring at home...	The point about causing unnecessary anxiety, made in the rationale, is important. These tools should only be recommended if they are appropriate for the individual, following discussion and person-centred decision making.
Asthma UK and the British	Guideline	Investigations Referral	[NEW] Consider supported self-monitoring at home...	We agree with the recommendation to facilitate supported self-monitoring of Long COVID breathlessness symptoms at home, where this is appropriate. However, given the changeable nature of Long COVID symptoms we would also recommend that this is

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Lung Foundation				followed-up with appropriate lung function tests should symptoms worsen – one of the main the purposes being once again to exclude other respiratory conditions.
Public Health Scotland	Guideline	Investigations Referral	[NEW] Consider supported self-monitoring at home...	Is this actually available everywhere?
Long COVID Scotland Action Group	Guideline	Investigations Referral	[NEW] Consider supported self-monitoring at home...	• It's important to reiterate understanding of how these devices should be used, for example in dysautonomia, pulse oximetry can give false drops on O2. • It's worth noting that this is torturous for some patients who would understandably prefer health professionals to do the monitoring. This needs to be clear as patients may struggle to take measurements due to brain fog etc.
Long COVID Physio	Guideline	Investigations Referral	[NEW] Consider supported self-monitoring at home...	The World Physiotherapy "activity diary:" for tracking activity, rest, and sleep, would be a useful addition this this section https://world.physio/sites/default/files/2021-06/WPTD2021-ActivityTracker-Final-v1.pdf
Long Covid SOS	Guideline	Investigations Referral	[NEW] Consider supported self-monitoring at home...	It should be noted that many people are now wearing wearable devices and have been before their conditions. They would welcome discussing any changes that they have noticed.
Patient-Led Research Collaborative	Guideline	Investigations Referral	[NEW] Consider supported self-monitoring at home...	Self-monitoring of heart rate and blood pressure should include instructions on how to measure orthostatic vitals if the person is experiencing dizziness or other indications of orthostatic intolerance. A person's ability and capacity to do this accurately on their own or with help should be assessed as part of shared decisionmaking.
The National Guideline Centre (ME/CFS guideline committee)	Guideline	Investigations Referral	[NEW] Consider supported self-monitoring at home...	We aren't clear why self-monitoring has been included in this section on further investigations and referral. We support the principle of self-monitoring as a self-management tool, the inclusion of self- monitoring in this section implies it is a tool for investigation and diagnosis. This recommendation would be better placed back in section 8.1 on self-management and supported self-management

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The National Guideline Centre (ME/CFS guideline committee)	Guideline	Investigations Referral	[NEW] Consider supported self-monitoring at home...	We aren't clear why self-monitoring has been included in this section on further investigations and referral. We support the principle of self-monitoring as a self-management tool, the inclusion of self- monitoring in this section implies it is a tool for investigation and diagnosis. This recommendation would be better placed back in section 8.1 on self-management and supported self-management.
Sheffield ME and Fibromyalgia Group (inc long COVID)	Guideline	Investigations Referral	[NEW] Consider supported self-monitoring at home...	This is welcomed. For some patients the severity of their symptoms can include sound and light sensitivity and hospital environments cannot cater for these needs.
Royal College of Paediatrics and Child Health	Guideline	Investigations Referral	[NEW] Consider supported self-monitoring at home...	Self and/or parent/carer monitoring. The reviewer was unsure they would ever recommend home BP monitoring in children. • Suggest removing this section. • Concerns about suggesting self-monitoring as this can easily lead to hypervigilance in both parents and children- if the GP/Paediatrician not concerned about pathology the reviewer would not advise this. • P45 exercise tolerance- suggest stick to sit to stand test as 6-minute walk test difficult to achieve in primary/secondary. • Care and this refers to COPD as well so not appropriate. • Agree postural symptoms should be assessed by lying and standing BP- the guide here suggests they are common but in section 1.6 the guideline does not include palpitations as it says they aren't common, consistency is needed.
Long Covid Support	Guideline	Investigations Referral	[NEW] Consider supported self-monitoring at home...	Someone's capacity to do this accurately and to seek help needs to be assessed as part of this shared decision making involving family and carers if needed.
NHS England	Guideline	Investigations Referral	[NEW] Consider supported self-monitoring at home...	Advice and written information provided must be communicated in a culturally competent way, in particular paying attention to the risk of digital exclusion.

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NHS England	Guideline	Investigations Referral	[NEW] Consider supported self-monitoring at home...	This recommendation is not flagged as new in the guideline
Welsh Government	Guideline	Investigations Referral	3.7 [UPDATED] Offer a chest X-ray by 12 weeks…	Does this need to be firmer? – offer and ensure CXR undertaken by 12w if…
Office for the Chief Allied Health Professions (AHP) Officer at NHS England and Improvement	Guideline	Investigations Referral	3.7 [UPDATED] Offer a chest X-ray by 12 weeks…	The office for the Chief AHP Officer queries if this should be a low dose high resolution (non-contrasted) CT Scan. Our question is what is the definitive diagnostic imaging in this instance?
Royal College of General Practitioners	Guideline	Investigations Referral	3.7 [UPDATED] Offer a chest X-ray by 12 weeks…	Can the committee please place more emphasis on the fact that even though a patient may have a clear x-ray they may still have underlying pathology. Please consider adding “be aware that a patient may have serious lung pathology despite a normal chest X ray”. This is in line with guidance for Chest X ray for all lung conditions.
UK Doctors Long Covid	Guideline	Investigations Referral	3.7 [UPDATED] Offer a chest X-ray by 12 weeks…	Consider adding ‘Be aware that a plain chest x-ray may not be sufficient to rule out lung disease and a normal x-ray in the context of ongoing respiratory symptoms should not rule out referral for further investigations or a secondary care opinion’
Asthma UK and the British Lung Foundation	Guideline	Investigations Referral	3.7 [UPDATED] Offer a chest X-ray by 12 weeks…	As mentioned above, we believe that in addition to chest X-rays it would be helpful for healthcare professionals to carry out lung function tests such as spirometry as standard, to help better identify and diagnose the root cause of the individual’s breathlessness. As mentioned earlier, guidance is likely to be needed to assist with identifying those who would benefit from other lung function tests and signposting to advice on carrying these out safely,

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				in line with the Primary Care Respiratory Society spirometry guidance https://www.pcrs-uk.org/news/new-update-spirometry-guidance .
PACS19 Post Acute Covid Syndrome 19 support group	Guideline	Investigations Referral	3.7 [UPDATED] Offer a chest X-ray by 12 weeks…	scintigraphy and highly specialised scans are required eg nuclear medicine to see a lot of the damage, xrays rarely for the most part, show much damage in the majority of our patients who had them.
Long COVID Scotland Action Group	Guideline	Investigations Referral	3.7 [UPDATED] Offer a chest X-ray by 12 weeks…	• This needs to be done sooner than 'by 12 weeks' if patients are experiencing symptoms like chest pain and breathlessness – the system needs to prevent anyone from reaching that stage. • It's crucial to add that a chest x-ray doesn't rule out heart inflammation or other serious heart issues.
Long Covid SOS	Guideline	Investigations Referral	3.7 [UPDATED] Offer a chest X-ray by 12 weeks…	It would be interesting to know how many people with LC have had abnormalities found on X-ray.
Royal College of Paediatrics and Child Health	Guideline	Investigations Referral	3.7 [UPDATED] Offer a chest X-ray by 12 weeks…	• Suggest add and ensure cardiac causes of chest pain, cough and shortness of breath are considered. • GENERAL- you need a cardiac section especially as there are reports of myocarditis, suggesting when to do ECG, or CXR or echocardiogram. P47- liaison CAMHS instead of psychiatry- need something about CYP mental health here.
Long Covid Support	Guideline	Investigations Referral	3.7 [UPDATED] Offer a chest X-ray by 12 weeks…	"Be aware a plain x-ray may not be sufficient" - so why is the recommendation not to do more than the basic because often people get told the x-ray is normal and are then not followed up. Seek to offer multidisciplinary tests to reduce the need for patients to attend multiple appointments (although some people may prefer shorter appointments). Consider the impact of missed pathology due to insufficiently discerning imaging techniques.
British Thoracic Society	Guideline	Investigations Referral	3.7 [UPDATED] Offer a chest X-ray by 12 weeks…	Suggest amending to incorporate the BTS guidelines for patients post-hospitalisation: https://www.bsti.org.uk/media/resources/files/Resp_follow_up_guidance_post_covid_pneumonia.pdf The current statement seems more appropriate for community managed patients rather than those admitted with pneumonitis Suggest adding mental health support to the

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				recommendation about urgent psychiatric assessment. Advise following the IAPT guidance (or similar for other nations) for assessment using short objective validated questionnaires
NHSEI - Specialised commissioning	Guideline	Investigations Referral	3.7 [UPDATED] Offer a chest X-ray by 12 weeks…	This recommendation is not flagged as updated in the guideline.
NHSEI - Specialised commissioning	Guideline	Investigations Referral	3.7 [UPDATED] Offer a chest X-ray by 12 weeks…	Whilst I agree a normal chest X-ray does not preclude disease (eh lung fibrosis), A chest X-ray that is abnormal at 12 weeks should prompt referral. Failure of resolution of pneumonic change can be a sign of malignacy
Faculty of Pain Medicine of the Royal College of Anaesthetists	Guideline	Investigations Referral	3.10 [UPDATED] After ruling out acute or life-threatening complications...	The testimonial evidence on reasons for lack of pain services in Scotland: "Concern re historical lack of services for other conditions CFS/ME, chronic pain, fibromyalgia, LTC management" (Locke, 2021) translated into this recommendation (3.10). Concerned that using the term 'any other relevant service' is too vague, especially when a) other services are lacking b) poorly resourced 'other' services are usually ringfenced, by means of clear exclusion criteria. A more specific statement would be helpful.
Welsh Government	Guideline	Investigations Referral	3.10 [UPDATED] After ruling out acute or life-threatening complications...	This highlights the need for clear local arrangements
Royal College of Speech and Language Therapists (RCSLT)	Guideline	Investigations Referral	3.10 [UPDATED] After ruling out acute or life-threatening complications...	The RCSLT recommends that the multidisciplinary team includes speech and language therapists for specialist input. Speech and language therapists support people post-COVID with any of the following: ongoing / persistent voice disorders; swallowing difficulties (dysphagia), laryngeal sensitivity or communication difficulties. These symptoms can exist on their own or be related to other common COVID symptoms, for example fatigue, respiratory challenges, cough or breathlessness. Patterson et al 2020. COVID-19 and ENT SLT services, workforce and research in the UK https://onlinelibrary.wiley.com/doi/10.1111/1460-6984.12565 Archer et al 2021.

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				Swallowing and Voice Outcomes in Patients Hospitalized With COVID-19: An Observational Cohort Study https://pubmed.ncbi.nlm.nih.gov/33529610/
Royal College of Occupational Therapists	Guideline	Investigations Referral	3.10 [UPDATED] After ruling out acute or life-threatening complications...	We are in agreement with the comments made in the rationale, indicating that early referral to multi-disciplinary support is essential, for all of the reasons stated. However, in practice, an early referral may not result in early support, due to existing capacity issues within community rehabilitation teams. The preferences of the person should be at the forefront of this decision making. Disparities in assessment and service provision should be highlighted within the Equality Impact Assessment, as the person's preferred option may not be available, which impacts inequalities. It would be beneficial to give greater clarity on what an 'other relevant service' might be, the relevant professionals, and for what purpose e.g. occupational therapy input to address goals related to daily activities, through a local community rehabilitation service.
UK Doctors Long Covid	Guideline	Investigations Referral	3.10 [UPDATED] After ruling out acute or life-threatening complications...	This is good provided such a service is available as many services are not following the NHSE model of a truly multidisciplinary assessment service with a clinician lead.
Asthma UK and the British Lung Foundation	Guideline	Investigations Referral	3.10 [UPDATED] After ruling out acute or life-threatening complications...	We agree with this recommendation.
Department of Health - Northern Ireland	Guideline	Investigations Referral	3.10 [UPDATED] After ruling out acute or life-threatening complications...	One concern was noted from a commissioning perspective on page 47. The advice is to 'consider referring people to an integrated MD assessment service …at any time from 4 weeks after the start of acute Covid-19'. The rationale was that in the panel's experience, the earlier the people received help, the more effective the interventions. The ONS surveys show that the % of people with symptoms reduces substantially between week 4 and week 12 without the services being in place. So if lots of people who would have got better on their own are referred that could be construed as success? There is no argument that

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				everyone needs to wait until they pass a 12 week mark, but opening the doors widely to those with symptoms at 4 weeks is potentially wasteful of resources and may delay assessment for everyone.
Long COVID Scotland Action Group	Guideline	Investigations Referral	3.10 [UPDATED] After ruling out acute or life-threatening complications...	• Mention what some of the life-threatening issues are if these aren't already included. • Again, people may need support prior to 4 weeks.
Long Covid SOS	Guideline	Investigations Referral	3.10 [UPDATED] After ruling out acute or life-threatening complications...	This is really important and should be in bold.
The National Guideline Centre (ME/CFS guideline committee)	Guideline	Investigations Referral	3.10 [UPDATED] After ruling out acute or life-threatening complications...	The deletion of 'if available' is welcomed as this could be result in perpetuating differences in access to care however 'other relevant services' is vague and would benefit from examples of the type of services.
The National Guideline Centre (ME/CFS guideline committee)	Guideline	Investigations Referral	3.10 [UPDATED] After ruling out acute or life-threatening complications...	The deletion of 'if available' is welcomed as this could be result in perpetuating differences in access to care however 'other relevant services' is vague and would benefit from examples of the type of services.
SIGN Council Scottish Intercollegiate	Guideline	Investigations Referral	3.10 [UPDATED] After ruling out acute or life-threatening complications...	LTE guideline version for SH's may present significant challenges in terms of community resource. While we agree that this could improve access and identify those people still struggling with symptoms and delays in access, currently we have no pathway for people with ongoing COVID 19 Syndrome and no additional resource to meet this demand.

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Royal College of Paediatrics and Child Health	Guideline	Investigations Referral	3.10 [UPDATED] After ruling out acute or life-threatening complications...	P.47 the reviewer thought the referral to integrated multidisciplinary assessment service was at 12 weeks not 4 weeks.
Royal College of Psychiatrists	Guideline	Investigations Referral	3.10 [UPDATED] After ruling out acute or life-threatening complications...	The guidance references 'integrated multidisciplinary assessment clinics", but could expand on the detail of who will staff them. Liaison psychiatrists are one group who have a unique skillset of relevance. The guidance could also be clearer on whether this is different to the later mentioned multidisciplinary rehabilitation teams.
Long Covid Support	Guideline	Investigations Referral	3.10 [UPDATED] After ruling out acute or life-threatening complications...	If people are in vulnerable or high-risk groups consider this referral before 4 weeks especially where services are running waiting lists. Early signposting to self-management and access to multidisciplinary services at the point of ongoing need are essential. Referrals are easier to cancel than to speed up. Do consider discussing with people access to private services if faced with long waiting lists in order to proactively reduce the risk of further complications created by waiting. Of course this is not available to everyone due to cost but advise people to consider charitable funding, insurance or support they may be able to access via their employer/school. Some GP practices have their own occupational therapy or physiotherapy services - consider the role of AHPs with people with complex presentations. Consider also the role of social services and reablement services in looking at equipment, housing adaptations and care. Consider that distress often ensues from inadequate management of physical symptoms (e.g. pain, cognitive impairment preventing barring return to work or education), lack of access to healthcare, and also that chronic sympathetic nervous system response can be a symptom of dysautonomia; it is important to understand the source of psychological or psychiatric symptoms to determine whether psychological/psychiatric referral is appropriate. Also consider PANS/PANDAS in children and adults if onset of psychiatric symptoms is sudden and treat this appropriately (including

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				with antibiotics) if suspected. These may be a reflection of frustrating intolerable symptoms, lack of validation and difficulty navigating the system rather than a primary psychological disorder. Consider that it is also a normal human response to disabling and unexplained symptoms to experience some anxiety or depressive symptoms. As well as to sudden life change. Review with people the impact of social pressures, e.g. finance, caring responsibilities, pressure to return to work whilst unwell and signpost to services that can support with these.
Long Covid Wales	Guideline	Investigations Referral	3.10 [UPDATED] After ruling out acute or life-threatening complications...	The problem here is that in primary care it may not be possible to rule out acute or life-threatening complications because the tests necessary to do so may not be available, even if the medical expertise to direct them is. Hence, it is critical for patients to be referred to a medical Consultant-led service for triage and onward investigation.
British Thoracic Society	Guideline	Investigations Referral	3.10 [UPDATED] After ruling out acute or life-threatening complications...	4 weeks is contentious due to the volume of unnecessary referrals it will trigger Agree complex patients with severe symptoms and impact after 4 weeks should not be declined by integrated multi-disciplinary teams However, many patients' symptoms will resolve by 12 weeks and a lighter touch approach to start maybe all that is necessary eg seen in primary care with signposting to Your Covid Recovery or similar which is mentioned in the self-management section (the tiered approach is mentioned here to) There's currently no evidence to suggest when to add in the multi-disciplinary assessment but if many patients after 4 weeks are referred (who will get better within 12 weeks) the services will become quickly overwhelmed and will be ineffective to most patients. There is plenty of evidence from the section on prevalence of symptoms to use to support that most patients will get better by 12 weeks Suggest rephrasing and perhaps reordering the sections so that the self-management section and tiered approach is discussed first and then the section on investigation and referral
NHSEI - specialised commissioning	Guideline	Investigations Referral	3.10 [UPDATED] After ruling out acute or life-	Consider signposting to charities and voluntary sector organisations for culturally appropriate support. Ensure any diagnosis of Long Covid is appropriately coded in local systems.

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			threatening complications...	
NHSEI - specialised commissioning	Guideline	Investigations Referral	3.10 [UPDATED] After ruling out acute or life-threatening complications...	Most people are still symptomatic at 4 weeks. Referral at 4 weeks will not only swamp services (delaying time to referral for those who need it) but is also likely to cause undue alarm in those (who will then have to wait for their assessment) for whom re-assurance on the natural time course for recovery would have been appropriate.
Welsh Government	Guideline	Investigations Referral	3.11 [UPDATED] Do not exclude people from referral...	Absolutely. This is consistent with previous messages and a helpful narrative
Royal College of Occupational Therapists	Guideline	Investigations Referral	3.11 [UPDATED] Do not exclude people from referral...	We are in full agreement with this recommendation.
Asthma UK and the British Lung Foundation	Guideline	Investigations Referral	3.11 [UPDATED] Do not exclude people from referral...	We agree with this recommendation. We have anecdotally heard from people sharing concerns that they feel they are not believed by HCPs – this recommendation could potentially help with these perceptions and is therefore welcome.
Public Health Scotland	Guideline	Investigations Referral	3.11 [UPDATED] Do not exclude people from referral...	Supportive of this
Long COVID Scotland Action Group	Guideline	Investigations Referral	3.11 [UPDATED] Do not exclude people from referral...	• Additionally include antibody tests; people shouldn't be excluded for not having these or for them being negative • It's worth noting there is recent evidence that circa 30% people with Long Covid do not make antibodies.
Long Covid SOS	Guideline	Investigations Referral	3.11 [UPDATED] Do not exclude people from referral...	We welcome this explicit statement. We find it disappointing even though the first guidelines stated they covered a clinical diagnosis, people have been denied access to services due to not having a positive test result.

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Patient-Led Research Collaborative	Guideline	Investigations Referral	3.11 [UPDATED] Do not exclude people from referral...	We support and endorse this addition.
Long Covid Support	Guideline	Investigations Referral	3.11 [UPDATED] Do not exclude people from referral...	or if people have a complex multi-systemic presentation.
British Thoracic Society	Guideline	Investigations Referral	3.11 [UPDATED] Do not exclude people from referral...	This recommendation is not flagged as updated in the guideline. Without presentation of (or clear reference to) the patient experience evidence, it's not possible to comment on whether this recommendation is valid or not.
NHSEI - specialised commissioning	Guideline	Investigations Referral	3.11 [UPDATED] Do not exclude people from referral...	Ok But in those who have an unclear history of acute covid and a negative (N-protein) antibody further thought should be given to an alternative explanation for symptoms – Once plugged into the 'long covid' pathway – the risk is everything tends to be labelled as 'long covid'
National Institute of Health Research (NIHR)	Guideline	Planning Care	4.1 [UPDATED] After the holistic assessment, discuss with the person...	on p.33 you have a consensus recommendation that a screening tool should be used. I am not aware of any research validating any tools. There is already considerable unwarranted variation throughout the UK in referrals and acceptance at specialist Long Covid clinics. There is a danger that unvalidated tools become an informal standard and there is potential to exclude people without justification I am surprised that the evidence review did not include the large, retrospective records reviews from the USA (Daugherty et al 2021, Al-Aly et al 2021, Spotnitz et al 2021l, Fair Health 2021) which all use control controls and samples of at least 250,000. They all identify risks that should inform care planning. Whilst they have methodological limitations, the included studies have more limitations
Royal College of Occupational Therapists	Guideline	Planning Care	4.1 [UPDATED] After the holistic assessment, discuss with the person...	As noted in the rationale, a tiered approach is important in making the best use of the available resources within an already over-stretched rehabilitation system.

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UK Doctors Long Covid	Guideline	Planning Care	4.1 [UPDATED] After the holistic assessment, discuss with the person...	Please emphasise that the initial assessment should be thorough, face to face and involve a full examination.
Asthma UK and the British Lung Foundation	Guideline	Planning Care	4.1 [UPDATED] After the holistic assessment, discuss with the person...	We would suggest that recommendations indicate in a clearer way, the eligibility criteria in which HCPs will determine; Long COVID patients who will be guided to self-manage and those who will be referred into other multidisciplinary and specialist services.
Polymyalgia Rheumatica and Giant Cell Arteritis Scotland (PMR-GCA Scotland)	Guideline	Planning Care	4.1 [UPDATED] After the holistic assessment, discuss with the person...	Ensure that any support or care offered can be delivered on a realistic timescale and at a location accessible to the patient.
Public Health Scotland	Guideline	Planning Care	4.1 [UPDATED] After the holistic assessment, discuss with the person...	? include referral to an integrated multidisciplinary assessment service 'if available'
Long COVID Scotland Action Group	Guideline	Planning Care	4.1 [UPDATED] After the holistic assessment, discuss with the person...	• Again, it is biased to put the self-management at the top of the list regardless of the intention of a tiered approach. Referral should be first; having secondary care last indicates unconscious bias around chronic illness. • Shared-decision making should also be mentioned here.
Faculty of Intensive Care Medicine	Guideline	Planning Care	4.1 [UPDATED] After the holistic assessment, discuss with the person...	These recommendations seem reasonable. Note: there is overlap with NICE CG83 and NICE QS158 (Quality Statement 4: follow-up after critical care discharge)
Long Covid SOS	Guideline	Planning Care	4.1 [UPDATED] After the holistic assessment, discuss with the person...	The terms holistic and initial assessment seem to be interchangeable in different sections. It would help if they are used consistently.

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Patient-Led Research Collaborative	Guideline	Planning Care	4.1 [UPDATED] After the holistic assessment, discuss with the person...	Provide resources including online peer support groups and information on pacing.
Royal College of Paediatrics and Child Health	Guideline	Planning Care	4.1 [UPDATED] After the holistic assessment, discuss with the person...	General comment to replace “the person “with “the child or young person” on p.48 and throughout. Referral to specialist care for specific complications. This should be ‘and’ not ‘or’ i.e., if referral to specialist care, they still likely need support from integrated and coordinated primary care etc.
Long Covid Support	Guideline	Planning Care	4.1 [UPDATED] After the holistic assessment, discuss with the person...	Initial assessment should be face to face and include a physical examination Clearer guidance required on what a ‘supported-self management’ model should look like and what minimum standards of care it should meet, as well as protocols for red flags reported into the system by the patient. People should be informed of how they can come back to seek referral onto other services if self-management is not sufficient or in the light of new and ongoing symptoms or challenges. Practitioners should advise patients on the existence and benefits of joining peer support groups such as offered by charitable organisation Long Covid Support (www.LongCovid.org), which also provides social and wellbeing activities. When considering referral to specialist services please consider concurrent referral rather than a test to rule out, then refer, then test to rule out, then refer. Consider setting up local services in a way to support people with concurrent testing to reduce burden of attending for testing.
NHSEI - specialised commissioning	Guideline	Planning Care	4.1 [UPDATED] After the holistic assessment, discuss with the person...	Advice and written information provided must be communicated in a culturally competent way, in particular paying attention to the risk of digital exclusion
NHSEI - specialised commissioning	Guideline	Planning Care	4.1 [UPDATED] After the holistic assessment, discuss with the person...	Add a bullet point: consider developing a personalised care and support plan or Personalised Wellbeing plan

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NHSEI - specialised commissioning	Guideline	Planning Care	4.1 [UPDATED] After the holistic assessment, discuss with the person...	This recommendation is not flagged as updated in the guideline
NHSEI - specialised commissioning	Guideline	Planning Care	4.1 [UPDATED] After the holistic assessment, discuss with the person...	Agree, but point out theses are not mutually exclusive
Royal College of Occupational Therapists	Guideline	Planning Care	4.2 [UPDATED] Use shared decision making to agree…	It is important to recognise the inequality of availability here. The most effective and preferred option for the person may not be available locally. There is disparity in service provision and format, the make up of multi-disciplinary teams, as well as waiting times.
UK Doctors Long Covid	Guideline	Planning Care	4.2 [UPDATED] Use shared decision making to agree…	This is fine provided a thorough face to face initial assessment has been done.
Asthma UK and the British Lung Foundation	Guideline	Planning Care	4.2 [UPDATED] Use shared decision making to agree…	For this recommendation, we would reiterate our comments related to the updated 4.1 section above.
Long COVID Scotland Action Group	Guideline	Planning Care	4.2 [UPDATED] Use shared decision making to agree…	• This is stronger than other sections, though 'listen to' should be added alongside 'think about' as patients will have already thought about this and may be very knowledgeable.
Long Covid SOS	Guideline	Planning Care	4.2 [UPDATED] Use shared decision making to agree…	This is highly reliant on the patient being given adequate time before an appointment to prepare and having information to any previous tests etc. It should be explicit that the information on what has been decided should be available to the patient afterwards in an accessible format for use as an ongoing guide. This is not currently always occurring.
SIGN Council Scottish Intercollegiate	Guideline	Planning Care	4.2 [UPDATED] Use shared decision making to agree…	This is an excellent recommendation!

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Royal College of Paediatrics and Child Health	Guideline	Planning Care	4.2 [UPDATED] Use shared decision making to agree…	Think about the overall impact their symptoms are having on their life, consider adding in…such as functional skills, attendance at education or work, and involvement in recreational activities even if each individual symptom alone may not warrant referral.
Long Covid Support	Guideline	Planning Care	4.2 [UPDATED] Use shared decision making to agree…	As long as an initial face to face assessment has been done With respect to fluctuating symptoms consider early referral into services that support an open referral back policy, e.g. can they access basic advice and support now but contact them again if support needs increase/change. If the burden of the overall impact is high consider referral to address easily managed symptoms even where it would not normally meet the threshold for input.
Long Covid Wales	Guideline	Planning Care	4.2 [UPDATED] Use shared decision making to agree…	Shared decision making is important, but it should be noted that for those suffering from impaired cognition and "brain fog" it can be akin to asking a drunk driver if they can operate a motor vehicle safely, so this and similar comments should be tempered accordingly.
British Dietetic Association	Guideline	Planning Care	4.2 [UPDATED] Use shared decision making to agree…	We need to make people aware of how their nutrition may have changed, even without them noticing. Ensuring other members of the MDT are using nutritional screening tools and promoting self-assessment tools during the assessment and monitoring of people with covid-19 is imperative. Nutritional care is not only about symptom management, rehabilitation is likely to be most effective where nutrition is optimised. People identified for rehab should be advised of this and directed to trustworthy resources (See Wojzischke et al., 2020. Nutritional status and functionality in geriatric rehabilitation patients: a systematic review and meta-analysis and van Wijngaarden et al., 2020. Effects of nutritional interventions on nutritional and functional outcomes in geriatric rehabilitation patients: A systematic review and meta-analysis.)
NHSEI - specialised commissioning	Guideline	Planning Care	4.2 [UPDATED] Use shared decision making to agree…	Consideration of the health inequality drivers that may contribute to their symptoms, impact on service accessibility/engagement and overall recovery trajectory.

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NHSEI - specialised commissioning	Guideline	Planning Care	4.2 [UPDATED] Use shared decision making to agree…	It may be helpful to say “People need good health literate information after acute COVID-19…”
NHSEI - specialised commissioning	Guideline	Planning Care	4.2 [UPDATED] Use shared decision making to agree…	ok
Welsh Government	Guideline	Management	[NEW] Be aware that there is a lack of evidence on the effectiveness of pharmacological treatments…	Should this be stronger and an explicit message added – consequently pharmacological treatments should not be prescribed unless as part of a ratified clinical trial.
Royal College of General Practitioners	Guideline	Management	[NEW] Be aware that there is a lack of evidence on the effectiveness of pharmacological treatments…	Can the committee consider adding the term 'nationally approved' into the line referring to clinical trials to ensure the safety of any patients seeking to participate in clinical research. Please consider using “However, participation in nationally approved clinical trials……”
Royal College of Occupational Therapists	Guideline	Management	[NEW] Be aware that there is a lack of evidence on the effectiveness of pharmacological treatments…	There is also a lack of evidence on the effectiveness of rehabilitation and self-management approaches, however rehabilitation teams are capturing quantitative and qualitative outcome data locally, and this will be valuable in informing recommendations moving forward, while the evidence base is established.
UK Doctors Long Covid	Guideline	Management	[NEW] Be aware that there is a lack of evidence on the effectiveness of pharmacological treatments…	There is some evidence for pharmacological treatments for certain specific symptom groups and pharmacological treatments should be considered for these patients, why has the Delphi paper by Nurek et al (https://bjgp.org/content/early/2021/07/27/BJGP.2021.0265) not been considered? Why does pharmacological treatment fall under self-management and supported self-management? Whilst it is correct say that there are no RCTs on pharmaceutical treatment for Long Covid per se there is increasing evidence for underlying

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				pathological mechanisms (eg mast cell activation or autonomic dysfunction) for which there is good evidence for the use of medication and widespread anecdotal evidence for the use of these medications in the management of patients with Long Covid. The overarching statement of the lack of effectiveness of pharmacological therapies is too strong and personalised informed trials of medications should be offered to patients based on their symptom profiles.
Asthma UK and the British Lung Foundation	Guideline	Management	[NEW] Be aware that there is a lack of evidence on the effectiveness of pharmacological treatments…	Nothing further to add on this recommendation.
Department of Health - Northern Ireland	Guideline	Management	[NEW] Be aware that there is a lack of evidence on the effectiveness of pharmacological treatments…	It is very helpful to have the statement on lack of evidence of effectiveness, with subsequent signposting to clinical trial participation.
PACS19 Post Acute Covid Syndrome 19 support group	Guideline	Management	[NEW] Be aware that there is a lack of evidence on the effectiveness of pharmacological treatments…	Not much consideration has been given to non pharmacological treatments. At the next expert panel meeting we would like to send some experts who can indicate very good progress with some non pharmaceutical treatments
Long COVID Scotland Action Group	Guideline	Management	[NEW] Be aware that there is a lack of evidence on the effectiveness of pharmacological treatments…	• Good to suggest trials – could patients be given links, so the burden of research isn't with the patient? • There is evidence for treatments for MCAS and PoTS, which can be life-changing for people with LC who meet this criteria; it's worth specifically mentioning this. • This contradicts the next update.

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#MEAction UK	Guideline	Management	[NEW] Be aware that there is a lack of evidence on the effectiveness of pharmacological treatments…	Why have the committee singled out pharmacological treatments here, when there is also a lack of evidence of effectiveness for psychological treatments? It is vital for those considering psychological treatments (whether through the NHS or privately) to understand the lack of evidence base for them in order to give their informed consent. The committee have noted that "it is not known if over-the-counter vitamins and supplements are helpful, harmful or have no effect" The committee must make clinicians and patients equally aware of the lack of evidence for psychological treatments.
Long COVID Physio	Guideline	Management	[NEW] Be aware that there is a lack of evidence on the effectiveness of pharmacological treatments…	It should be noted there is some emerging evidence (eg: anti-histamines) that should be discussed, even if low quality https://www.medrxiv.org/content/10.1101/2021.06.06.21258272v1 (this also applies to the statement about over the counter medications page 50)
Faculty of Intensive Care Medicine	Guideline	Management	[NEW] Be aware that there is a lack of evidence on the effectiveness of pharmacological treatments…	These recommendations seem reasonable. Note: there is overlap with NICE CG83 and NICE QS158 (Quality Statement 4: follow-up after critical care discharge)
Long Covid SOS	Guideline	Management	[NEW] Be aware that there is a lack of evidence on the effectiveness of pharmacological treatments…	We would welcome acknowledgement of some of the treatments being used in the clinic setting to alleviate symptoms which are similar to other conditions such as tachycardia in this section. We find it concerning that it is stated that there is little evidence on interventions when respiratory (and other forms of) physio can certainly help. We know that patient support groups can help but these are all run by volunteers and provision of adequate services should be built into the health and social care system.
Patient-Led Research Collaborative	Guideline	Management	[NEW] Be aware that there is a lack of evidence on the effectiveness of	FDA-approved or over the counter medications as well as vitamin or electrolyte supplements may be helpful for indicated illnesses (e.g., headache, anxiety) or documented deficiencies (e.g., vitamin deficiency) after carefully weighing the benefits and risks of pharmaceutical interventions. Some treatments have been offered that lack evidence of

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			pharmacological treatments…	efficacy or effectiveness, and could be harmful to patients. Healthcare professionals should inquire about any unprescribed medications, herbal remedies, supplements, or other treatments that patients may be taking for their post-COVID conditions. -- from US CDC post-COVID Conditions guidance
Royal College of Paediatrics and Child Health	Guideline	Management	[NEW] Be aware that there is a lack of evidence on the effectiveness of pharmacological treatments…	8.1 is aimed at adults e.g., housing.
Long Covid Support	Guideline	Management	[NEW] Be aware that there is a lack of evidence on the effectiveness of pharmacological treatments…	Particularly consider the role of the nervous system, dysautonomias etc for treatments that can respond well to medication. Some clinicians have been using medications for almost a year now with success, such as the UCL clinic, it is disappointing that they were not invited to give expert testimony. It is profoundly unhelpful to leave a void here and just tell people there's no evidence when these treatments are being used in some settings. It is also somewhat naive of the panel to suppose that because the guideline says that there is no evidence, this will stop people from buying OTC and self medicating. People are desperate, they are reading all sorts of things online, some bone fide, some not, and are trying them to see if they work. It would be far more helpful if NICE could consult with expert clinicians who are using antihistamines and other medications to treat MCAS, POTS and other forms of dysautonomia and make suggestions of medications which are unlikely to be harmful but may be of benefit. The risk profile of OTC antihistamines is such that they could easily be recommended on the basis of expert testimony without the need for RCTs. Similarly, potentially HRT to help with symptoms. There is evidence from the ZOE app that those on HRT have reduced symptoms compared to similar age cohort not on HRT. Support people to review the use of over the counter vitamins and supplements especially with regards to their existing medication and conditions. Advise on anything commonly suggested online that is clearly contraindicated. e.g.from USA CDC long covid guidelines: "FDA-approved or

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				over the counter medications as well as vitamin or electrolyte supplements may be helpful for indicated illnesses (e.g., headache, anxiety) or documented deficiencies (e.g., vitamin deficiency) after carefully weighing the benefits and risks of pharmaceutical interventions. Some treatments have been offered that lack evidence of efficacy or effectiveness, and could be harmful to patients. Healthcare professionals should inquire about any unprescribed medications, herbal remedies, supplements, or other treatments that patients may be taking for their post-COVID conditions." We are surprised that Nurek et al was not considered to be evidence https://bjgp.org/content/early/2021/07/27/BJGP.2021.0265
Long Covid Wales	Guideline	Management	[NEW] Be aware that there is a lack of evidence on the effectiveness of pharmacological treatments…	Yes, but this should not preclude prescribing medicines with a low risk profile and potential benefit as found by existing sufferers, including, but not limited to, e.g. NSAIDs, H1 & H2-blockers and beta-blockers. patients will understand that there is no magic treatment overall for Long COVID, but they will be willing to try well known medicines to see if they alleviate symptoms on the understanding that they may not work in any given individual - a principle that applies to all prescriptions for medicines! And collating responses to such medicines would rapidly provide an evidence base.
NHSEI - specialised commissioning	Guideline	Management	[NEW] Be aware that there is a lack of evidence on the effectiveness of pharmacological treatments…	Mention should be given not just to pharmacological treatments but to other perceived but unproven and potentially harmful interventions including herbal remedies and lifestyle (e.g. dietary) modifications, use of which may be more prevalent in certain demographic groups. Providers should ensure provision of culturally appropriate communication and resources around research to promote equitable access to participate in research trials. Research staff should ensure their contact information is readily available to healthcare professions to ensure resources that promote representative trial participation are maximised.
NHSEI - specialised commissioning	Guideline	Management	[NEW] Be aware that there is a lack of evidence on the effectiveness of pharmacological treatments…	The rationale for this recommendation is insufficient as it is practically a verbatim repetition of the recommendation.

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NHSEI - specialised commissioning	Guideline	Management	[NEW] Be aware that there is a lack of evidence on the effectiveness of pharmacological treatments…	Agree – perhaps a stronger warning against remedies proving popular via social media – theses are common and potentially dangerous
Welsh Government	Guideline	Management	[NEW] Follow current national and local guidance for managing common symptoms...	Agree. A consistent measured approach is helpful
Royal College of Speech and Language Therapists (RCSLT)	Guideline	Management	[NEW] Follow current national and local guidance for managing common symptoms...	There is a mismatch between national guidance and NICE guidance which makes it difficult for community services to interpret and apply guidance into practice. This could also pose a clinical risk to the end user. The RCSLT recommends that voice and swallowing difficulties are added to the symptom list in NICE. Your COVID Recovery clearly signposts people to information on dysphagia and voice, yet this isn't mentioned in the NICE guidelines. This risks confusing patients and allowing them to experience poor health outcomes due to a lack of services. In order to support consistency of approach and for services to be commissioned in line with patient expectations as suggested in Your COVID Recovery, NICE should list core access to speech and language therapy.
Public Health England	Guideline	Management	[NEW] Follow current national and local guidance for managing common symptoms...	Regarding the recommendation about vitamins (bottom of page 50), given that it states there is no evidence whether vitamins may make the condition better or worse, although there are anecdotal reports about overdose then clarification on reason why we want people to avoid taking vitamins, should be clarified.
Royal College of Occupational Therapists	Guideline	Management	[NEW] Follow current national and local guidance for managing common symptoms...	As noted previously, gathering outcomes data and expert testimony from local rehabilitation services will be valuable in developing consensus approaches to effective rehabilitation and treatment approaches.

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UK Doctors Long Covid	Guideline	Management	[NEW] Follow current national and local guidance for managing common symptoms...	Please amend to 'using established treatments, for example antihistamines for skin rashes, allergic conditions and mast cell dysfunction, beta blockers for persistent tachycardia provided concerning arrhythmias excluded, colchicine for pericarditis/myocarditis etc'
Asthma UK and the British Lung Foundation	Guideline	Management	[NEW] Follow current national and local guidance for managing common symptoms...	We know that people affected by Long COVID are desperately seeking information and support and we therefore welcome this recommendation, signposting people to Your COVID Recovery and NHSInform. Asthma UK and the British Lung Foundation have also recently developed resources to support with managing breathlessness and increasing physical activity levels: Long COVID | British Lung Foundation (blf.org.uk). We have also collaborated with a number of other charities to develop holistic support so Long COVID patients can manage all of their symptoms in one place rather than getting, for example information on managing neurological problems in one place, breathlessness in another, or cardiovascular support in a third place. We would be pleased to have these resources shared within guidelines to further support people with their recovery.
Long COVID Scotland Action Group	Guideline	Management	[NEW] Follow current national and local guidance for managing common symptoms...	• Your COVID Recovery is generally not helpful to people with LC as it does not reflect the breadth of experiences of those who were not hospitalised; NHS Inform also focuses on a small number of symptoms and overstates anxiety, which could lead to stigma (see previous comments on this). • This contradicts the last update and will confuse GPs.
Long COVID Physio	Guideline	Management	[NEW] Follow current national and local guidance for managing common symptoms...	This is problematic for those experiencing fatigue or post-exertional symptom exacerbation as current national and local guidelines promote exercise as a rehabilitation intervention, which is not endorsed by all current rehab guidelines. https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-2021_0.pdf https://www.albertahealthservices.ca/assets/info/ppih/if-ppih-covid-19-rehab-allied-health-practice-considerations-post-covid.pdf#page38 https://physiotherapy.ca/sites/default/files/site_images/Advocacy/long_covid_en-final-rev2.pdf https://www.csp.org.uk/system/files/publication_files/001745_Community%20Rehab%20St

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				andards_A4_V7.pdf https://www.csp.org.uk/system/files/publication_files/001745_Hospital%20Standards_A4_V10_3.pdf https://apps.who.int/iris/bitstream/handle/10665/344472/WHO-EURO-2021-855-40590-59892-eng.pdf?sequence=1&isAllowed=y This is why explicitly including post-exertional symptom exacerbation in the list of common symptoms is required to ensure that safe and effective care is provided.
Long Covid SOS	Guideline	Management	[NEW] Follow current national and local guidance for managing common symptoms...	We welcome the possibility of established treatments being included. We note that antihistamines have been suggested for rashes, although some doctors are stating other benefits such as management of Mast Cell Activation Syndrome in those with Long Covid.
The National Guideline Centre (ME/CFS guideline committee)	Guideline	Management	[NEW] Follow current national and local guidance for managing common symptoms...	The panel agreed there is 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 (such as 'brain fog'). We have noted in the comment above for section 1.3 there is potential for confusion in the diagnosis of Post Covid-19 syndrome and ME/CFS and we are very concerned about the reference to 'Your COVID Recovery'. In Your COVID Recovery the advice on 'keeping active/getting moving again' describes graded exercise therapy with fixed increments. Graded exercise therapy is included as a 'do not' recommendation in the draft ME/CFS guideline for people with ME/CFS. In addition this recommendation could result in people following the advice on keeping active/getting moving again without any professional supervision, this appear at odds with the referral to services earlier in the guideline and in recommendation 5.5 below. We note that in the draft ME/CFS guideline energy management and physical activity programmes are supported by specialist healthcare professionals with appropriate training and expertise. We recommend the link is removed.
The National Guideline Centre	Guideline	Management	[NEW] Follow current national and local	The panel agreed there is 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 (such as 'brain fog'). We have noted in the comment above for section 1.3 there is potential

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(ME/CFS guideline committee)			guidance for managing common symptoms...	for confusion in the diagnosis of Post Covid-19 syndrome and ME/CFS and we are very concerned about the reference to 'Your COVID Recovery'. In Your COVID Recovery the advice on 'keeping active/getting moving again' describes graded exercise therapy with fixed increments. Graded exercise therapy is included as a 'do not' recommendation in the draft ME/CFS guideline for people with ME/CFS. In addition this recommendation could result in people following the advice on keeping active/getting moving again without any professional supervision, this appear at odds with the referral to services earlier in the guideline and in recommendation 5.5 below. We note that in the draft ME/CFS guideline energy management and physical activity programmes are supported by specialist healthcare professionals with appropriate training and expertise. We recommend the link is removed.
Sheffield ME and Fibromyalgia Group (inc long COVID)	Guideline	Management	[NEW] Follow current national and local guidance for managing common symptoms...	It is critical that health professionals understand post-exertional malaise (PEM) and can advise patients. For those patients who experience PEM, they must be advised to rest and to use pacing to manage their daily activities in order to prevent deterioration. This evidence is well-reviewed in the ME/CFS guideline. May patients with post-COVID-19 syndrome are experiencing the same symptoms and while this condition is poorly understood, the evidence for the management of these symptoms must be drawn from the work done by NICE on the new draft ME/CFS guideline in order to prevent patient's deterioration.
Royal College of Paediatrics and Child Health	Guideline	Management	[NEW] Follow current national and local guidance for managing common symptoms...	p.50 consider adding support around diet, sleep, activity management, wellbeing- may be not enough evidence.
Long Covid Support	Guideline	Management	[NEW] Follow current national and local guidance for managing common symptoms...	I thought NICE role is to provide national guidance, that will in part help to reduce the regional variation in services. By driving not only a focus on assessment but management of symptoms this document would support Long Covid Clinics to look beyond assessment to intervention and support. Your Covid Recovery is quite superficial from a health care

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				provider and even from a patient perspective. I would also suggest other NICE guidance on associated conditions, as well as symptom specific links e.g. british heart and lung foundations, ME association, etc. It would be great to ensure better links and more thorough information is included in Your Covid Recovery, although appreciate this is no the remit of NICE and consultation on YCR is ongoing.
Long Covid Wales	Guideline	Management	[NEW] Follow current national and local guidance for managing common symptoms...	Indeed, as per the previous comment regarding supposed lack of evidence of medicines.
NHSEI - Specialised commissioning	Guideline	Management	[NEW] Follow current national and local guidance for managing common symptoms...	Fine – but this is the national guidance is it not?
Welsh Government	Guideline	Management	5.3 [UPDATED] Support people in discussions with their employers...	This would be in line with standard practice. There is a wider debate to be had about the availability of occupational health clinicians and their role.
Faculty of occupational medicine (FOM)	Guideline	Management	5.3 [UPDATED] Support people in discussions with their employers...	Specific mention of the positive impact of return to work /education outcomes supported by occupational health professionals – Sign post to access to work
The Society and College of Radiographers	Guideline	Management	5.3 [UPDATED] Support people in discussions with their employers...	There is perhaps a heading missing for the third Consensus recommendation on page 41
Royal College of General Practitioners	Guideline	Management	5.3 [UPDATED] Support people in discussions with their employers...	The rationale for this recommendation contains a useful comment about supporting flexible working or working from home for those experiencing the long-term effects of COVID-19, however the recommendation itself fails to recognise this. Some patients may never fully recover and therefore it would be useful to recognise that these changes to working life

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				may be permanent and that people may require reasonable adjustments under the disability discrimination act.
Royal College of Occupational Therapists	Guideline	Management	5.3 [UPDATED] Support people in discussions with their employers...	Occupational therapists are playing a vital role in supporting people to return to work and education, both in specialist occupational health and vocational rehabilitation settings, as well as within community rehabilitation services. Local rehabilitation services are gathering outcomes data that indicates the impact of therapeutic interventions on people's ability to return to work. This data could help to inform future intervention planning, and future revisions of these guidelines.
Asthma UK and the British Lung Foundation	Guideline	Management	5.3 [UPDATED] Support people in discussions with their employers...	We have no comments on this recommendation.
Long COVID Scotland Action Group	Guideline	Management	5.3 [UPDATED] Support people in discussions with their employers...	• Good but the last line needs to be mentioned earlier as it may not be read. It is – important to emphasise that this is a chronic illness and phased returns can take months, which employers aren't accustomed to.
Long COVID Physio	Guideline	Management	5.3 [UPDATED] Support people in discussions with their employers...	Please include the following guidance on return to work specific to Long COVID: - For returning workers https://www.som.org.uk/COVID-19_return_to_work_guide_for_recovering_workers.pdf - For managers https://www.som.org.uk/COVID-19_return_to_work_guide_for_managers.pdf?fbclid=IwAR3EfGr81n53BrLji0ZmLn1AAOPqGFGjXZDR9NdL_p2vaZyebvJQPZMAHNI - https://www.gov.uk/access-to-work - https://chronicillnessinclusion.org.uk/2021/05/05/i-already-have-a-job-getting-through-the-day/ - https://www.nhsemployers.org/articles/supporting-recovery-after-long-covid?fbclid=IwAR259ce61P9FcoAKTFrryWCw7tBsZmlojs8JVf3UVnqlmCn5L0BQcbUVXhQ - http://www.ahpf.org.uk/files/Guidance-on-completion-of-AHP-Health-and-Work-Report.pdf

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Long Covid SOS	Guideline	Management	5.3 [UPDATED] Support people in discussions with their employers...	Information for family on what to expect of people who are having to pace and are unable to do as much as they previously could would also be welcome. Long Covid has an impact on caring responsibilities as well as work.
Patient-Led Research Collaborative	Guideline	Management	5.3 [UPDATED] Support people in discussions with their employers...	Include examples of other accommodations (i.e. teleworking, changing job roles, flextime).
Sheffield ME and Fibromyalgia Group (inc long COVID)	Guideline	Management	5.3 [UPDATED] Support people in discussions with their employers...	Acknowledge that for some, a return to work may not be possible.
Royal College of Paediatrics and Child Health	Guideline	Management	5.3 [UPDATED] Support people in discussions with their employers...	Again school, college and employer last, study or work from home, flexible return to education. Adults to be replaced with young adults.
Long Covid Support	Guideline	Management	5.3 [UPDATED] Support people in discussions with their employers...	Reference should be made here to the Society of Occupational Medicine Covid-19 return to work guide for recovering workers. Reference should be made to understanding that previous national guidance on return to work did not always meet the needs of those with chronic and particularly energy limiting chronic illness. Guide doctors to make reference to post-Covid-19 syndrome on fit notes due to the impact this may have on them in an employment, managing attendance, sickness and ill health context. Consider the length of fit notes provided. Sometimes it may be better to provide a longer fit notes rather than frequent shorter ones that add pressure to be back to work by the time they run out. Used shared decision making here and an understanding of the person, how they respond to internal and external pressures and how supportive their employers are. Remember that fit notes can be ended early if needed. Ensure that people have accessed their occupational health service for support (and trade union if a member). Recommend use of the AHP

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				Health and Work report supplementary to fit notes for complex cases likely to need prolonged phased returns and/or amended duties. Give people guidance of the likely impact on their symptoms of a return to work that is not guided by these principles. Early input on pacing via occupational therapy or physiotherapy can get people into routines and patterns of activity that are health sustaining and they can review this with people as they return to work, making adjustments as needed. Consider the role of work as rehabilitation and for supportive employers the ability to work very short, flexible hours from home on key but not time restricted projects can help people to feel part of the workplace. Sometimes these can be 'keeping in touch' days, work trials etc and not part of an official phased return. Also consider the role of supporting people to remain socially part of their work team but also by guiding employers and colleagues to see taking part in social activities whilst off sick as part of someone's recovery and not simply an indication they are well enough to be back at work. People are frightened of the view that workplaces will take if they step foot outside their home when signed off. From the Expert Testimonial there was mention of trying to increase and establish occupational therapy services in primary care to get people back into employment. We would support this approach, much of this work could also be provided virtually which means therapists can be recruited from remote locations. For children, similar liaison with schools and education services should take place around possible accommodations such as extra time on tests, scheduled rest breaks, a modified timetable, arrangements for school trips. Children should have access to support from the school nurse, school counselor and pastoral term, who should be educated on the issues faced by children experiencing ongoing issues due to COVID-19. Who defines reduced performance. Is it about impaired performance? Recognise that when people are well they may take on more at work than is expected. Support people to identify with their employer essential and desirable tasks and activities, do this with children and schools too. Aim to include tasks that bring joy and satisfaction as well as those that may be deemed easy for them or within their capabilities. Be aware that people with ongoing symptoms may prioritise work or education about other activities such as self-care, exercise, home or

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				social activities, therefore this guidance should consider reduction performance and activity across all areas to be significant so as not to prioritise work and education only. Suggest to change wording to "...reduced performance or activity levels in education work, self-care, exercise, social or other areas may need….."
Long Covid Wales	Guideline	Management	5.3 [UPDATED] Support people in discussions with their employers...	This is a critically important point. Practitioners should support patients and point out to employers etc that given it is a new disease the clinical course of Long COVID is uncertain as to severity and time, and variation with time, although generally there is improvement with time, but not necessarily complete. Hence, individuals should be supported to carry out such tasks as they feel they can, when they can, commensurate with the principle of pacing regarding symptoms of Long COVID in general.
NHSEI - Specialised commissioning	Guideline	Management	5.3 [UPDATED] Support people in discussions with their employers...	This recommendation is not clear. Does it mean the clinician should encourage their patient to have a discussion with their employer or does it mean that the clinician should actively participate in providing support in discussions with employers (eg writing letter, having a joint meeting etc)
NHSEI - Specialised commissioning	Guideline	Management	5.3 [UPDATED] Support people in discussions with their employers...	Where appropriate, patients should be signposted to the appropriate support services, including social prescribers. Crucially, "education, work or training" should not be considered as the only functional impacts of long Covid as this risks isolating those who are unable to work or participate in education, for example individuals with certain disabilities. Functional assessments should be comprehensive, inclusive, and tailored to each patient's individual circumstances and needs.
NHSEI - Specialised commissioning	Guideline	Management	5.3 [UPDATED] Support people in discussions with their employers...	agree
Welsh Government	Guideline	Management	5.4 [UPDATED] Include physical, psychological and psychiatric aspects of rehabilitation…	The wider context of this narrative, whilst well intended, may create blocks to initiating / undertaking rehab.

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Office for the Chief Allied Health Professions (AHP) Officer at NHS England and Improvement	Guideline	Management	5.4 [UPDATED] Include physical, psychological and psychiatric aspects of rehabilitation…	The office for the Chief AHP Officer support the view of a holistic model of rehabilitation and that it is explained that rehabilitation is not just physical.
Faculty of occupational medicine (FOM)	Guideline	Management	5.4 [UPDATED] Include physical, psychological and psychiatric aspects of rehabilitation…	Multidisciplinary recovery pathways based in the workplace could be mentioned with the benefits of adjustments in the workplace such as remote working, altered hours of work, coaching and mentorship. Psychological rehab and assessment – interested in whether this would be within the specialist MDT or filtered into usual services. Usual services may not have the expertise and timelines might not align well with other intervention due to waiting lists but there is an argument for upskilling usual primary care mental health services in long term conditions especially where we expect high prevalence. Inclusion exclusion criteria if this will be carried out in the specialist service may be tricky, especially if this will be accessible by self referral.
Royal College of Occupational Therapists	Guideline	Management	5.4 [UPDATED] Include physical, psychological and psychiatric aspects of rehabilitation…	Occupational therapists are recording data locally on the interventions that they are completing with people affected by Long COVID. The most frequent interventions typically relate to fatigue management, work, self-management and cognition. Additionally, pain management, sleep management, anxiety and mood management are common needs.
UK Doctors Long Covid	Guideline	Management	5.4 [UPDATED] Include physical, psychological and psychiatric aspects of rehabilitation…	Could this be phrased 'include physical and mental health aspects……' rather than the need to state both psychological and psychiatric?
Asthma UK and the British	Guideline	Management	5.4 [UPDATED] Include physical, psychological	We agree with this recommendation.

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Lung Foundation			and psychiatric aspects of rehabilitation…	
Long COVID Scotland Action Group	Guideline	Management	5.4 [UPDATED] Include physical, psychological and psychiatric aspects of rehabilitation…	• It's important to specifically mention PSE/PEM and the risks of graded exercise and heart and other organ damage here – they won't necessarily know this or consider this, especially the point around GET.
#MEAction UK	Guideline	Management	5.4 [UPDATED] Include physical, psychological and psychiatric aspects of rehabilitation…	Due to the lack of knowledge and understanding about ME/CFS and post-exertional malaise, specific mention of the potential for harm from graded exercise therapies should be made here.
Long COVID Physio	Guideline	Management	5.4 [UPDATED] Include physical, psychological and psychiatric aspects of rehabilitation…	Suggested inclusion into the phraseology: Phased return to work should be person-centred, flexible and if required extended, dependent on the symptomatic and episodic presentation of Long COVID. Important to recognise the episodic nature of Long COVID and the consequential implications on return to work and labour-force participation as referenced in this citation https://gh.bmj.com/content/6/9/e007004
Long Covid SOS	Guideline	Management	5.4 [UPDATED] Include physical, psychological and psychiatric aspects of rehabilitation…	It would be useful to stress the physical rehabilitation. The offer of psychological rehabilitation when there is nothing being offered for the physical symptoms, may not be welcomed by the patient.
Patient-Led Research Collaborative	Guideline	Management	5.4 [UPDATED] Include physical, psychological and psychiatric aspects of rehabilitation…	Please use caution in including psychological and psychiatric terms in the context of rehabilitation, given the history of prior harm done to persons with ME/CFS by recommending GET/CBT based on flawed data from PACE trial, and given persons with Long COVID are being diagnosed with ME/CFS. We recommend removing the terms "psychological and psychiatric" entirely here to avoid this issue. Rehabilitation for fatigue should be targeting pacing, and if that is what is intended by saying psychological/psychiatric aspects of rehabilitation, in must be made much clearer, as it is

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				not clear currently. Support for post-exertional malaise should be part of the person's rehabilitation program.
The National Guideline Centre (ME/CFS guideline committee)	Guideline	Management	5.4 [UPDATED] Include physical, psychological and psychiatric aspects of rehabilitation…	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. It's 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 National Guideline Centre (ME/CFS guideline committee)	Guideline	Management	5.4 [UPDATED] Include physical, psychological and psychiatric aspects of rehabilitation…	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. It's 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.’
Royal College of Paediatrics and Child Health	Guideline	Management	5.4 [UPDATED] Include physical, psychological and psychiatric aspects of rehabilitation…	Suggest including ‘social’ in the rehabilitation list. People in the rationale paragraph to be changed to children, young people and their families/carers. Again, breathlessness in this paragraph but had been taken away in section 1.6, suggest leave it in as a common symptom i.e., exclude from exclusionary symptoms in 1.6.
Long Covid Support	Guideline	Management	5.4 [UPDATED] Include physical, psychological and psychiatric aspects of rehabilitation…	Reference should be made here to the World Physiotherapy briefing paper on safe rehabilitation for people living with Long COVID. Equal weight should be given to these aspects. Beware over psychologising, dismissing people’s experience of physical signs and symptoms or incorrectly attributing them to a psychological cause whilst demonstrating understanding of the complex interplay between mind and body. Consider putting in place

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				a formal mechanism for patients to record adverse effects from rehabilitation activity, akin to the Yellow Card scheme for pharmacological treatments. This is especially important when people begin to improve and increase their activity. Keeping a record to help identify patterns and triggers can be a useful self management and rehabilitation aid. Clinicians and patients should be made aware that post exertional symptom exacerbation can occur 12-48 hours after activity. Consider giving specific examples in regards to symptoms that could affect the persons being able to start rehabilitation. e.g. heart conditions, micro embolisms, post exertional malaise. But including these specific things it will help highlight these important risks to healthcare professionals who may other wonder what this is referring to.
NHSEI - Specialised commissioning	Guideline	Management	5.4 [UPDATED] Include physical, psychological and psychiatric aspects of rehabilitation…	I don't understand the statement "Include physical, psychological and psychiatric aspects of rehabilitation to guide management." Could this be re-phrased for clarity?
NHSEI - Specialised commissioning	Guideline	Management	5.4 [UPDATED] Include physical, psychological and psychiatric aspects of rehabilitation…	agree
Welsh Government	Guideline	Management	5.5 [UPDATED] Work with the person to develop a personalised rehabilitation and management plan...	This is needed for success.
Royal College of General Practitioners	Guideline	Management	5.5 [UPDATED] Work with the person to develop a personalised rehabilitation and management plan...	Can the committee please add "rehabilitation specialists" to this recommendation to ensure it is clear who should undertake this part of care? The only people qualified to write a rehabilitation prescription are those specialising in this area and we do not want to undermine their role or create confusion over roles and responsibilities. We suggest: "rehabilitation specialists should work with the person……"

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Royal College of Speech and Language Therapists (RCSLT)	Guideline	Management	5.5 [UPDATED] Work with the person to develop a personalised rehabilitation and management plan...	There is a mismatch between COVID guidance and the rehabilitation prescription. This creates a clinical risk. In order to create consistency the RCSLT recommends adding dysphagia, voice and communication as these issues are clearly covered by the rehabilitation prescription.
Royal College of Occupational Therapists	Guideline	Management	5.5 [UPDATED] Work with the person to develop a personalised rehabilitation and management plan...	It is important to acknowledge local variation in the availability of services and duration of therapeutic input. There is inequality in access currently, and services may not be available to meet the goals identified within the rehabilitation and management plan.
Personalised Care Group NHSE/I	Guideline	Management	5.5 [UPDATED] Work with the person to develop a personalised rehabilitation and management plan...	We recommend that all healthcare professionals developing shared decision making and management plans be trained in personalised care decision making via the personalised care institute https://www.personalisedcareinstitute.org.uk/your-learning-options/
Asthma UK and the British Lung Foundation	Guideline	Management	5.5 [UPDATED] Work with the person to develop a personalised rehabilitation and management plan...	We agree with this recommendation.
Long COVID Scotland Action Group	Guideline	Management	5.5 [UPDATED] Work with the person to develop a personalised rehabilitation and management plan...	• See previous comment – these points also need to be repeated here. • It is also important to listen to the patient.
#MEAction UK	Guideline	Management	5.5 [UPDATED] Work with the person to develop a personalised rehabilitation and management plan...	We support the additional updated recognition of fluctuating symptoms.

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Long COVID Physio	Guideline	Management	5.5 [UPDATED] Work with the person to develop a personalised rehabilitation and management plan...	Include World Physiotherapy briefing paper 9 into the rationale https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-2021_0.pdf
Long Covid SOS	Guideline	Management	5.5 [UPDATED] Work with the person to develop a personalised rehabilitation and management plan...	This is vague (maybe necessarily) given the range of symptoms. We suggest that this reinforces the fact that Long Covid should be managed by doctors/teams who have specific experience in this condition rather than in primary care We are slightly concerned about the repeated use of 'goals' given the issues experienced by some who are put on to graded exercise programmes and who subsequently have to de-register from them due to Post Exertional Malaise (PEM). Goal-setting may not be appropriate for all as targets may be missed with relapses. There is no information on how cognitive rehabilitation will occur. As this is key for maintaining work performance and being able to continue in a job, this seems to be a key omission
Patient-Led Research Collaborative	Guideline	Management	5.5 [UPDATED] Work with the person to develop a personalised rehabilitation and management plan...	Rehabilitation plan should include pacing. Come to a shared understanding that rehabilitation may not result in getting back to baseline (pre-Covid), but about learning to manage symptoms alongside activity demands.
The National Guideline Centre (ME/CFS guideline committee)	Guideline	Management	5.5 [UPDATED] Work with the person to develop a personalised rehabilitation and management plan...	Recommendation 5.5 refers to unspecified 'interventions', without reference to potential harms, is concerning. For people who have symptoms consistent with ME/CFS, the recommendations on management 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. We welcome the recognition that symptoms may fluctuate.
The National Guideline Centre (ME/CFS	Guideline	Management	5.5 [UPDATED] Work with the person to develop a personalised rehabilitation and management plan...	Recommendation 5.5 refers to unspecified 'interventions', without reference to potential harms, is concerning. For people who have symptoms consistent with ME/CFS, the recommendations on management in the draft ME/CFS guideline should be considered. Any programme of rehabilitation should be delivered or overseen by a physiotherapist or

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guideline committee)				occupational therapist with appropriate training and expertise. We welcome the recognition that symptoms may fluctuate.
Sheffield ME and Fibromyalgia Group (inc long COVID)	Guideline	Management	5.5 [UPDATED] Work with the person to develop a personalised rehabilitation and management plan...	Remove all mention goal-setting which causes patient's to 'push through' rather than respond to their body's tolerance levels. Patients feel failures, health professionals encourage them to try harder and the situation deteriorates. Sensitive advice about this fluctuating syndrome and the need for a management plan for a good day and for a bad day is more useful. Rest and time seem to be the only ways of supporting those with brainfog.
Royal College of Paediatrics and Child Health	Guideline	Management	5.5 [UPDATED] Work with the person to develop a personalised rehabilitation and management plan...	Work with the child, young person and family/carers. The reviewer suggests symptom diaries can be controversial and encourage anxiety and hypervigilance, and avoid distraction from symptoms as a technique, parents trying to be helpful may concentrate on symptoms rather than healthy distraction. More useful addition to monitor function and goals.
Long Covid Support	Guideline	Management	5.5 [UPDATED] Work with the person to develop a personalised rehabilitation and management plan...	"...breathlessness, fatigue and 'brain fog' are among the most commonly reported long?term symptoms" - also post exertional symptom exacerbation Highlight the fact that rehabilitation is not always about getting back to "normal" or baseline but about learning to live with and manage symptoms alongside activity demands. Plan with people how to identify and manage expected and unexpected fluctuations. Suggest to include the role of pacing and to acknowledge that goals can be quite simple things such as getting dressed e.g. change second bullet to "helping the person to understand the role of rest and pacing while working towards achievable goals that include daily self-care activities." Agree on having added bullet on symptom fluctuation, very helpful.
Long Covid Wales	Guideline	Management	5.5 [UPDATED] Work with the person to develop a personalised rehabilitation and management plan...	This is important because it is the patient, of course, who is best able to judge their performance at that moment which is critical with a disease that varies with time, even hour by hour.

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British Dietetic Association	Guideline	Management	5.5 [UPDATED] Work with the person to develop a personalised rehabilitation and management plan...	As advised by expert testimony, reliable sources of dietary advice should be made clear. As advised by expert testimony, referral to dietetics should be considered in the event of GI symptoms.
British Thoracic Society	Guideline	Management	5.5 [UPDATED] Work with the person to develop a personalised rehabilitation and management plan...	Refer to the BTS statement on COVID-19 rehab
NHSEI - Specialised commissioning	Guideline	Management	5.5 [UPDATED] Work with the person to develop a personalised rehabilitation and management plan...	Ensure that offers are made to invite an advocate to the participate in the development of the rehabilitation and management plan, particularly vulnerable patients, patients with underlying cognitive impairment or those suffering with cognitive symptoms as part of their COVID-19 syndrome and that communication is culturally competent to meet the patient's and advocates needs.
NHSEI - Specialised commissioning	Guideline	Management	5.5 [UPDATED] Work with the person to develop a personalised rehabilitation and management plan...	Include monitoring of symptoms as well as management, as this will help inform actions that need to be taken either in terms of self-management, or in seeking clinical advice.
NHSEI - Specialised commissioning	Guideline	Management	5.5 [UPDATED] Work with the person to develop a personalised rehabilitation and management plan...	ok
Royal College of Occupational Therapists	Guideline	Management	5.7 [UPDATED] Consider additional support for people...who may be vulnerable...	This will require integrated working between NHS teams, local authorities and third sector organisations. It is important to understand the criteria and capacity of non-NHS services to support this work. Symptoms of post COVID-19 syndrome may be overshadowed by other known conditions such as autism. A different approach may be required for young people and adults who experience both.

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Asthma UK and the British Lung Foundation	Guideline	Management	5.7 [UPDATED] Consider additional support for people...who may be vulnerable...	We agree with this recommendation, but we feel that, if possible, the offer should be extended to all people with Long COVID-related symptoms. This is primarily because, in our insights work, we have heard a few people describe their experiences after Covid-19, as 'isolating.'
Long COVID Scotland Action Group	Guideline	Management	5.7 [UPDATED] Consider additional support for people...who may be vulnerable...	• It is also worth mentioning children, parents and others with existing inequities or protected characteristics e.g. postcode lotteries, people of colour.
#MEAction UK	Guideline	Management	5.7 [UPDATED] Consider additional support for people...who may be vulnerable...	We support the addition of disabled people to this recommendation, however believe that those with severe ongoing symptoms should also be mentioned here, as access to services is likely significantly harder for this population, and they may also be in need of care packages.
Long Covid SOS	Guideline	Management	5.7 [UPDATED] Consider additional support for people...who may be vulnerable...	Glad to see this has been widened to all groups who may be classed as such.
Royal College of Paediatrics and Child Health	Guideline	Management	5.7 [UPDATED] Consider additional support for people...who may be vulnerable...	Top paragraph consensus about old people- could include vulnerable those with intellectual disability but needs changing.
Long Covid Support	Guideline	Management	5.7 [UPDATED] Consider additional support for people...who may be vulnerable...	This should include people with Long Covid who live alone, regardless of age, previous health pre-Covid-19, etc. . Also consider the role of support groups here and local third sector support.
NHSEI - Specialised commissioning	Guideline	Management	5.7 [UPDATED] Consider additional support for	It's not clear from the rationale why disabled people have been highlighted as a vulnerable cohort. Suggest 'people with complex needs' may be more appropriate and a more widely encompassing term.

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			people...who may be vulnerable...	
NHSEI - Specialised commissioning	Guideline	Management	5.7 [UPDATED] Consider additional support for people...who may be vulnerable...	What age would an older person be?
NHSEI - Specialised commissioning	Guideline	Management	5.7 [UPDATED] Consider additional support for people...who may be vulnerable...	ok
UK Doctors Long Covid	Guideline	Management	5.8 [DELETED] Consider referral from 4 weeks for specialist advice for children…	It is unclear why this comment was deleted, please explain.
Asthma UK and the British Lung Foundation	Guideline	Management	5.8 [DELETED] Consider referral from 4 weeks for specialist advice for children…	We have no comments on this recommendation.
Long COVID Scotland Action Group	Guideline	Management	5.8 [DELETED] Consider referral from 4 weeks for specialist advice for children…	• Cannot comment without seeing the full text but so far this guideline does not mention children much, and their need for specialist care.
The National Guideline Centre (ME/CFS	Guideline	Management	5.8 [DELETED] Consider referral from 4 weeks for specialist advice for children…	Deletion of this recommendation contradicts the draft ME/CFS guideline and referral of children at 4 weeks with symptoms consistent with ME/CFS (as noted above there is a potential for confusion between ME/CFS and post-COVID-19 syndrome and the difficulty in diagnosing which is which) this could result in delays in diagnosis and access to specialist care for children and young people.

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The National Guideline Centre (ME/CFS guideline committee)	Guideline	Management	5.8 [DELETED] Consider referral from 4 weeks for specialist advice for children…	Deletion of this recommendation contradicts the draft ME/CFS guideline and referral of children at 4 weeks with symptoms consistent with ME/CFS (as noted above there is a potential for confusion between ME/CFS and post-COVID-19 syndrome and the difficulty in diagnosing which is which) this could result in delays in diagnosis and access to specialist care for children and young people.
Long Covid Support	Guideline	Management	5.8 [DELETED] Consider referral from 4 weeks for specialist advice for children…	Unclear why this says 'deleted' when it says on page 65 lines 120-22 'It was suggested that using a post 12-week referral point might be a barrier for children. 'Post-COVID-19' suggests a time point, whereas it was suggested that children should be assessed over time as they may deteriorate progressively.
Long Covid Wales	Guideline	Management	5.8 [DELETED] Consider referral from 4 weeks for specialist advice for children…	No justification is given for deleting this section, so how is it possible to comment?
NHSEI - Specialised commissioning	Guideline	Management	5.8 [DELETED] Consider referral from 4 weeks for specialist advice for children…	How can a comment be made on a recommendation that has been deleted from the guideline and which isn't represented fully in this document?
Long COVID Scotland Action Group	Guideline	Follow-up..	6.1 [UPDATED] Agree with the person how often follow-up and monitoring…	• It's important to go into more depth about the case management and communication of specialist referrals. • In Scotland patients may be on several pathways
Royal College of	Guideline	Follow-up..	6.1 [UPDATED] Agree with the person how often	As noted previously, it is important to acknowledge local variation in the availability, capacity and delivery of services to provide follow-up and monitoring, which may lead to

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Occupational Therapists			follow-up and monitoring…	inequality of access and experience. Decision making should include parents / carers where appropriate.
Long Covid Support	Guideline	Follow-up..	6.1 [UPDATED] Agree with the person how often follow-up and monitoring…	Consider also the burden placed on the person in managing these reviews across settings. Can some of that be alleviated by using key workers, case managers to monitor external tests, assessments, bloods etc, and communicate regularly with the person results, outcomes and need for reassessment. Where services are not available and this puts people at risk consider some way to centrally note and monitor this. Early and consistent support is more likely to have better outcomes in terms of general health, wellbeing, employability/attendance in education than late or sporadic input.
NHS England	Guideline	Follow-up..	6.1 [UPDATED] Agree with the person how often follow-up and monitoring…	Consider health inequality drivers that may contribute to the patients' symptoms, impact on service accessibility/engagement and overall recovery trajectory.
Asthma UK and the British Lung Foundation	Guideline	Follow-up..	6.1 [UPDATED] Agree with the person how often follow-up and monitoring…	Nothing further to add on this recommendation.
The Society and College of Radiographers	Guideline	Follow-up..	6.1 [UPDATED] Agree with the person how often follow-up and monitoring…	Page No 46, recommendation(not numbered): Offer a chest X-ray by 12 weeks after acute COVID-19 only if the person has not already had one and they have continuing respiratory symptoms. Chest X-ray appearances alone should not determine the need for referral for further care. Be aware that a plain chest X-ray may not be sufficient to rule out lung disease. Comment: Might there also be cases where a person did have a previous chest X-ray but will need a repeat examination due to worsening symptoms? Also there may be requirement to follow up initial findings?
Royal College of Speech and Language	Guideline	Follow-up..	6.1 [UPDATED] Agree with the person how often	The ability to engage in shared decision making rests on good communication support, to enable the person to make informed decisions. As many vulnerable populations with communication difficulties are at higher risk of catching COVID, support must be provided

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Therapists (RCSLT)			follow-up and monitoring…	for communication. We are also concerned about widening inequalities due to digital poverty.
Faculty of Intensive Care Medicine	Guideline	Follow-up..	6.1 [UPDATED] Agree with the person how often follow-up and monitoring…	The evidence does not include testimony from any of the numerous examples of post-ICU clinics and programmes already in existence for managing patients with PICS. Many of these services also have significant experience in seeing patients after COVID-19-related critical illness. Patients with features of post-COVID-19 syndrome who are recovering after a critical illness are likely to benefit from, and should be referred to (if not already being follow-up) in a post-ICU clinic, in line with existing guidance (NICE CG83 and NICE QS158). This could be considered for inclusion in the updated consensus recommendation: “After ruling out life-threatening complications and alternative diagnoses, consider referring people to an integrated multidisciplinary assessment service of other relevant service any time from 4 weeks after the start of acute COVID-19”. For example by adding “Patients recovering after critical illness, including intensive care admission, following COVID-19 infection, should be referred to a critical care follow-up service in line with existing guidance (NICE CG83 and NICE QS158)”.
National Institute of Health Research (NIHR)	Guideline	Follow-up..	6.1 [UPDATED] Agree with the person how often follow-up and monitoring…	The 'expert' opinion seems to come from a very limited number of testimonies. Given the very wide range of opinions I'm not clear why they have primacy. The fact that one service has reduced investigations may be read as evidence that this is good practice. Large studies (referred to in my comments on section 4) identify significant sequelae in a small percentage of people. At present there is no evidence to predict who they will be and atypical findings mean that persistent symptoms should be re evaluated (including more detailed investigations).
Royal College of Paediatrics and Child Health	Guideline	Follow-up..	6.1 [UPDATED] Agree with the person how often follow-up and monitoring…	The reviewer thinks that child safeguarding needs to be considered here as well, and if a family are not bringing their child and they aren’t going to school, they need to be seen in person.

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Welsh Government	Guideline	Follow-up..	6.1 [UPDATED] Agree with the person how often follow-up and monitoring…	This is a reasonable objective, but other factors may include consideration of the potential to generate a dependency, and the reality of wider service provision.
NHS England	Guideline	Follow-up..	6.1 [UPDATED] Agree with the person how often follow-up and monitoring…	This recommendation is not flagged as updated in the guideline
British Dietetic Association	Guideline	Follow-up..	6.1 [UPDATED] Agree with the person how often follow-up and monitoring…	We need to make people aware of how their nutrition may have changed, even without them noticing. Ensuring other health professionals and members of the MDT are using nutritional screening tools and promoting self-assessment tools during the assessment and monitoring of patients with covid-19 is imperative.
Long Covid Wales	Guideline	Follow-up..	6.1 [UPDATED] Agree with the person how often follow-up and monitoring…	Yes, but this again relates back to comments about shared decision making. It is important, but it should be noted that for those suffering from impaired cognition and "brain fog" they may not be in a fit condition to comprehend, even decide and make fully informed comment on precise details of follow-up etc. All they wish to know is that care will be ongoing and someone is caring for them, which does a huge amount to alleviate anxiety and depression.
NHSEI - Specialised commissioning	Guideline		6.1 [UPDATED] Agree with the person how often follow-up and monitoring…	ok
Public Health Scotland	Guideline	Follow-up..	[NEW] Be alert to symptoms developing that could mean referral or investigation is needed...	? Add in that patients should be advised to report new symptoms?

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Long COVID Scotland Action Group	Guideline	Follow-up..	[NEW] Be alert to symptoms developing that could mean referral or investigation is needed...	Recommendations link does not work so cannot comment on assessment.
Long Covid Wales	Guideline	Follow-up..	[NEW] Be alert to symptoms developing that could mean referral or investigation is needed...	This is important given the variation with time of severity and type of symptoms and that systems can be affected that were previously normal, so previous test results may no longer apply, as with e.g. Systemic Lupus.
Royal College of Paediatrics and Child Health	Guideline	Follow-up..	[NEW] Be alert to symptoms developing that could mean referral or investigation is needed...	This relates to adults and military not applicable here.
Long COVID Physio	Guideline	Follow-up..	[NEW] Be alert to symptoms developing that could mean referral or investigation is needed...	This wording may need to avoid ambiguity and say “Be alert to symptoms developing over the trajectory of living with long COVID…” It is an opportunity to reference the “multidimensional, episodic and unpredictable nature of Long COVID” https://gh.bmj.com/content/6/9/e007004
Asthma UK and the British Lung Foundation	Guideline	Follow-up..	[NEW] Be alert to symptoms developing that could mean referral or investigation is needed...	We agree with this recommendation. I would point to our earlier comments on investigations and referrals as being relevant to this recommendation also.
Polymyalgia Rheumatica and Giant Cell Arteritis Scotland (PMR-GCA Scotland)	Guideline	Follow-up..	[NEW] Be alert to symptoms developing that could mean referral or investigation is needed...	We have received reports of recurrence of symptoms which were thought to have resolved many weeks before. Patients must be confident about whether and how to report these changes.

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Long Covid Support	Guideline	Follow-up..	[NEW] Be alert to symptoms developing that could mean referral or investigation is needed...	Who should be alert? Person, family, carers, GP, ...
NHSEI - Specialised commissioning	Guideline		[NEW] Be alert to symptoms developing that could mean referral or investigation is needed...	ok
Sheffield ME and Fibromyalgia Group (inc long COVID)	Guideline	Follow-up..	6.2 [UPDATED] Using shared decision making, discuss and agree plans for discharge…	Add: Ensure good and timely access to occupational therapy assessment and aids and adaptations to alleviate post-exertional malaise and fatigue. Offer a longer appointment time as needed.
Royal College of Occupational Therapists	Guideline	Follow-up..	6.2 [UPDATED] Using shared decision making, discuss and agree plans for discharge…	As noted in the expert testimony, given the fluctuating nature of needs and symptoms arising from post COVID-19 syndrome, it is also important to discuss the mechanisms for re-accessing support if needs appear or return after discharge. Decision making should include parents / carers where appropriate.
Long Covid SOS	Guideline	Follow-up..	6.2 [UPDATED] Using shared decision making, discuss and agree plans for discharge…	Concerned that 'rehabilitation' seems to be informed by the Nuffield programme which may be inappropriate to those who experience post-exertional malaise or exercise intolerance. Anecdotally amongst support groups, this programme had a high number of drop-outs.
NHS England	Guideline	Follow-up..	6.2 [UPDATED] Using shared decision making, discuss and agree plans for discharge…	Ensure that offers are made to invite an advocate to the participate in the decision-making process, particularly vulnerable patients, patients with underlying cognitive impairment or those suffering with cognitive symptoms as part of their COVID-19 syndrome and that communication is culturally competent to meet the patient's and advocates needs.
Royal College of Speech and	Guideline	Follow-up..	6.2 [UPDATED] Using shared decision making,	Given that there are particularly vulnerable groups, such as adults with learning disabilities who are at increased risk of contracting COVID, it must be recognised that individuals will

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Language Therapists (RCSLT)			discuss and agree plans for discharge…	need specialist support to communicate their needs, engage optimally with shared decision making and discuss and agree their future plans.
UK Doctors Long Covid	Guideline	Follow-up..	6.2 [UPDATED] Using shared decision making, discuss and agree plans for discharge…	Please include a statement about the possible need to re-enter the rehabilitation programme/access medical support if symptoms resurge or new symptoms develop. We need to determine the long term impact of COVID, everyone should be included on a register prior to discharge so that longitudinal surveillance can occur.
Long COVID Physio	Guideline	Follow-up..	6.2 [UPDATED] Using shared decision making, discuss and agree plans for discharge…	The Nuffield health programme promotes graded exercise therapy. It is unacceptable that this is being provided as an example of Long COVID rehabilitation when the service contradicts the warnings of NICE and rehab guidelines. https://www.nice.org.uk/guidance/gid-ng10091/documents/statement https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-2021_0.pdf https://www.albertahealthservices.ca/assets/info/ppih/if-ppih-covid-19-rehab-allied-health-practice-considerations-post-covid.pdf#page38 https://physiotherapy.ca/sites/default/files/site_images/Advocacy/long_covid_en-final-rev2.pdf https://www.csp.org.uk/system/files/publication_files/001745_Community%20Rehab%20Standards_A4_V7.pdf https://www.csp.org.uk/system/files/publication_files/001745_Hospital%20Standards_A4_V10_3.pdf https://apps.who.int/iris/bitstream/handle/10665/344472/WHO-EURO-2021-855-40590-59892-eng.pdf?sequence=1&isAllowed=y
NHS England	Guideline	Follow-up..	6.2 [UPDATED] Using shared decision making, discuss and agree plans for discharge…	This recommendation is not flagged as updated in the guideline, it is flagged as new
Royal College of Paediatrics	Guideline	Follow-up..	6.2 [UPDATED] Using shared decision making,	Transition to adult services should be mentioned. As self-management and supported self-management, maybe should be a contracted limit to input e.g., 2 years.

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and Child Health			discuss and agree plans for discharge…	
Long Covid Support	Guideline	Follow-up..	6.2 [UPDATED] Using shared decision making, discuss and agree plans for discharge…	Understand that people may choose to pay privately for complementary and ongoing support and do not remove services where they choose to do this. Consider supporting people to access non NHS assessment and care through charitable or employer/school funding where indicated. Understand that symptoms fluctuate and false recovery is common. People may need to be re-present at a later time. A registry or detailed longitudinal research is necessary to understand the features of the relapsing/remitting nature of Long Covid. Consider not fully discharging people with ongoing symptoms, as new research may highlight new tests or treatments that may otherwise not be picked up and the patient may miss out, possibly leading to patient safety risks., should ensure that they always stay in some service depending on symptoms e.g. refer on to ME.CFS or symptom specific service,s but keep in loop re. new symptoms and new treatments. Continued access to services, updates and information could be very beneficial mentally as symptoms may continue for months leading to frustration and depression, and physically to continue to encourage resting, pacing and take up any new evidence-based interventions. e.g. from the USA CDC long covid guidance “Continuing follow-up over the course of illness, with considerations of broadening the testing and management approach over time if symptoms do not improve or resolve, while remaining transparent that there is much more to learn about post-COVID conditions.”....”Knowledge of post-COVID conditions is likely to change rapidly with ongoing research. Healthcare professionals and patients should continue to check for updates on evolving guidance for post-COVID conditions.”
Asthma UK and the British Lung Foundation	Guideline	Follow-up..	6.2 [UPDATED] Using shared decision making, discuss and agree plans for discharge…	We agree with this recommendation for HCPs to consider the individual’s preferences, goals and social support.

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Long COVID Scotland Action Group	Guideline	Follow-up..	6.2 [UPDATED] Using shared decision making, discuss and agree plans for discharge…	Wouldn't the rehab teams handle the discharge?
Long Covid Wales	Guideline	Follow-up..	6.2 [UPDATED] Using shared decision making, discuss and agree plans for discharge…	Yes, but this again relates back to comments about shared decision making. It is important, but it should be noted that for those suffering from impaired cognition and "brain fog" they may not be in a fit condition to comprehend, even decide and make fully informed comment on precise details of follow-up etc. All they wish to know is that care will be ongoing and someone is caring for them, which does a huge amount to alleviate anxiety and depression. Also, given that the clinical course of Long COVID has yet to be perfectly defined, systems affected vary in time and severity, then the whole concept of 'discharge' is challenged in this respect, and patients should be allowed to refer themselves back to services directly without all the delay and risk with going back via primary care.
NHSEI - Specialised commissioning	Guideline		6.2 [UPDATED] Using shared decision making, discuss and agree plans for discharge…	ok
Long COVID Scotland Action Group	Guideline	Follow-up..	6.3 [DELETED] Tailor monitoring to people's symptoms and discuss any changes…	• Cannot comment without seeing the full text.
NHS England	Guideline	Follow-up..	6.3 [DELETED] Tailor monitoring to people's symptoms and discuss any changes…	How can a comment be made on a recommendation that has been deleted from the guideline and which isn't represented fully in this document?
Asthma UK and the British	Guideline	Follow-up..	6.3 [DELETED] Tailor monitoring to people's	It is unclear to us, why this paragraph is being removed.

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Lung Foundation			symptoms and discuss any changes…	
Long Covid Support	Guideline	Follow-up..	6.3 [DELETED] Tailor monitoring to people's symptoms and discuss any changes…	not clear why this was deleted, cannot access MAGICapp as password not provided
The National Guideline Centre (ME/CFS guideline committee)	Guideline	Follow-up..	6.3 [DELETED] Tailor monitoring to people's symptoms and discuss any changes…	See comments in section 3 where this recommendation has been moved to.
The National Guideline Centre (ME/CFS guideline committee)	Guideline	Follow-up..	6.3 [DELETED] Tailor monitoring to people's symptoms and discuss any changes…	See comments in section 3 where this recommendation has been moved to.
Long Covid Wales	Guideline	Follow-up..	6.3 [DELETED] Tailor monitoring to people's symptoms and discuss any changes…	Where is the justification for deleting this section?
Long COVID Scotland Action Group	Guideline	Follow-up..	6.4 [DELETED] Consider supported self-monitoring at home, for example heart rate…	• Cannot comment without seeing the full text.

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Royal College of Paediatrics and Child Health	Guideline	Follow-up..	6.4 [DELETED] Consider supported self-monitoring at home, for example heart rate…	Agree deleted.
NHS England	Guideline	Follow-up..	6.4 [DELETED] Consider supported self-monitoring at home, for example heart rate…	How can a comment be made on a recommendation that has been deleted from the guideline and which isn't represented fully in this document?
Long Covid Support	Guideline	Follow-up..	6.4 [DELETED] Consider supported self-monitoring at home, for example heart rate…	not clear why this was deleted, cannot access MAGICapp as password not provided
Asthma UK and the British Lung Foundation	Guideline	Follow-up..	6.4 [DELETED] Consider supported self-monitoring at home, for example heart rate…	We agree with removing this paragraph.
Long Covid Wales	Guideline	Follow-up..	6.4 [DELETED] Consider supported self-monitoring at home, for example heart rate…	Where is the justification for deleting this section?
Long Covid SOS	Guideline	Follow-up..	6.5 [UPDATED] Be alert to symptoms developing that could mean referral…	'However, they agreed that a discharge plan would support motivation and help to manage rehabilitation resources.' We have concerns over this statement due to the relapsing and remitting nature that many experience. It could be read as the needs of the healthcare system and meeting targets are more important than those of the patient. Language around discharge needs to be sensitive as well to reflect progress may not be linear in nature.

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Long COVID Scotland Action Group	Guideline	Follow-up..	6.5 [UPDATED] Be alert to symptoms developing that could mean referral…	• Have already commented on this above.
Public Health Scotland	Guideline	Follow-up..	6.5 [UPDATED] Be alert to symptoms developing that could mean referral…	As above
NHS England	Guideline	Follow-up..	6.5 [UPDATED] Be alert to symptoms developing that could mean referral…	Is this a different recommendation to the new recommendation in line 2, or the same recommendation? If it's the same recommendation is it new or updated or neither?
Faculty of occupational medicine (FOM)	Guideline	Follow-up..	6.5 [UPDATED] Be alert to symptoms developing that could mean referral…	self-monitoring – consider being alert for increase in anxiety related safety seeking or checking behaviours where self-monitoring is introduced or include information about this where self-monitoring is indicated
Long Covid Support	Guideline	Follow-up..	6.5 [UPDATED] Be alert to symptoms developing that could mean referral…	This point has not been updated on the COVID-19 rapid guideline: managing the long-term effects of COVID-19 document and should presumably be included at the end of Section 9 Follow Up on p55
Long COVID Physio	Guideline	Follow-up..	6.5 [UPDATED] Be alert to symptoms developing that could mean referral…	This wording may need to avoid ambiguity and say "Be alert to symptoms developing over the trajectory of living with long COVID…" It is an opportunity to reference the "multidimensional, episodic and unpredictable nature of Long COVID" https://gh.bmj.com/content/6/9/e007004
Asthma UK and the British Lung Foundation	Guideline	Follow-up..	6.5 [UPDATED] Be alert to symptoms developing that could mean referral…	We agree with this recommendation and have no further comments.
Long Covid Wales	Guideline	Follow-up..	6.5 [UPDATED] Be alert to symptoms developing that could mean referral…	Yes, but also be aware that as Long COVID is a new disease that patterns of symptoms and signs may not fit with previously taught and assumed patterns associated with other

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				diseases. Perhaps this general comment would be worth a comment up front in the guidance?
Long COVID Scotland Action Group	Guideline	Service Org	8.1 [UPDATED] Provide access to multidisciplinary services…for assessing...	Currently there are few multidisciplinary services in Scotland – this needs to be updated to reflect this with suggestions on how to manage where there are no tailored pathways
UK Doctors Long Covid	Guideline	Service Org	8.1 [UPDATED] Provide access to multidisciplinary services…for assessing...	If 'one-stop' clinic models are being used there needs to be a clear strategy in place for who will take the lead in coordinating the ongoing care of the patient particularly if input from multiple specialties is required. Ideally there should be a named clinician taking on this role and the information of who this is and how to contact them should be provided to the patient.
NHS England	Guideline	Service Org	8.1 [UPDATED] Provide access to multidisciplinary services…for assessing...	In addition, consider health inequality drivers that may have contributed to the varying presentation and illness trajectory of COVID-19 illnesses within the BAME population.
Faculty of Intensive Care Medicine	Guideline	Service Org	8.1 [UPDATED] Provide access to multidisciplinary services…for assessing...	No specific comments, seems reasonable. Note: there is overlap with NICE CG83 and NICE QS158 (Quality Statement 4: follow-up after critical care discharge)
British Thoracic Society	Guideline	Service Org	8.1 [UPDATED] Provide access to multidisciplinary services…for assessing...	Regarding the specialties listed such as neuro, rheum, cardio – a regular COVID MDT could be highlighted as a process to provide this expertise without necessitating referrals to multiple specialists (better for the patient pathway and the healthcare system), upskill the COVID team to deal with common issues and refer after discussion if still needed.
Faculty of occupational medicine (FOM)	Guideline	Service Org	8.1 [UPDATED] Provide access to multidisciplinary services…for assessing...	Suggest include occupational health specialists (NHS or independent Providers)
Royal College of Speech and Language	Guideline	Service Org	8.1 [UPDATED] Provide access to multidisciplinary services…for assessing...	The RCSLT recommends that the term multidisciplinary (MDT) clinic would be preferable to "one-stop" clinic as the patient with Long-COVID requires an MDT approach to care and input. This term is also more reflective of the differences in service delivery models across

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Therapists (RCSLT)				the United Kingdom. The RCSLT also recommends that the core team includes speech and language therapists to screen, assess and provide intervention to people with long-COVID with swallowing problems (independent of or related to fatigue), voice changes, dry mouth, taste and smell change, chronic cough and breathlessness, cognitive communication needs, fatigue or 'brain fog' related needs such as word-finding difficulty and concentration. The need for speech and language therapy is confirmed by the list of patient symptoms already identified by NICE, including breathlessness, cough and fatigue, where SLT has a key role in the management of each. The RCSLT is concerned that there is a mismatch between NICE and UK national guidance on long-COVID. NHSE's 'national guidance for post-COVID clinics' long-COVID includes speech and language therapists as a core member. In Northern Ireland national long-COVID assessment clinic proposals include funded SLT as a key part of the pathways. Even in areas where numbers of patients who need speech and language therapy are significant, business cases have failed because NICE does not list speech and language therapy as a core part of the team. This means that patient needs are not being met. This has long-term impact on clinical and mental health outcomes for the individual. There is already the caveat that it is based on local need, so there is no harm in listing us. This is creating a variation in practice, and inequalities in access, because we are aware that in other parts of the UK, speech and language therapists are seen as core to the multidisciplinary team.
Welsh Government	Guideline	Service Org	8.1 [UPDATED] Provide access to multidisciplinary services…for assessing...	There are a few elements that need consideration. The rationale was more helpful. I wonder if we should consider - there should be the opportunity to access to multidisciplinary services ... Why should the services should be led by a doctor?
The Society and College of Radiographers	Guideline	Service Org	8.1 [UPDATED] Provide access to multidisciplinary services…for assessing...	There is perhaps a heading missing for recommendation on p50?

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Public Health Scotland	Guideline	Service Org	8.1 [UPDATED] Provide access to multidisciplinary services…for assessing...	This is a good recommendation, but given the current state of the NHS and access to services, this may simply be not feasible - a comment regarding this must be added so that expectations are not damaged.
Long Covid Wales	Guideline	Service Org	8.1 [UPDATED] Provide access to multidisciplinary services…for assessing...	This is critically important, because current Welsh Government policy is for medical practitioners NOT to establish such clinics and so contradict NICE guidance, at considerable cost in terms of clinical risk, pain and suffering, and demands on other parts of the NHS, e.g. primary care and mental health services. This is especially so because many of the diagnostic tests required to exclude serious actionable pathology, such as heart failure, cardiac arrhythmia, thrombosis, complex endocrine failure, are not available to primary care in Wales (at least) and the Welsh Government's policy is to provide 'care closer to home' which it could be argued is a euphemism for keeping Long COVID patients away from the secondary care they require.
Long Covid SOS	Guideline	Service Org	8.1 [UPDATED] Provide access to multidisciplinary services…for assessing...	This is excellent but the onus is on the referring doctors to find such a multidisciplinary clinic and unfortunately few as described exist and none in the devolved health authorities. It is likely to be wanted by most if not all patients
NHS England	Guideline	Service Org	8.1 [UPDATED] Provide access to multidisciplinary services…for assessing...	This recommendation is not flagged as updated in the guideline
Asthma UK and the British Lung Foundation	Guideline	Service Org	8.1 [UPDATED] Provide access to multidisciplinary services…for assessing...	We agree with this recommendation.
Long Covid Support	Guideline	Service Org	8.1 [UPDATED] Provide access to multidisciplinary services…for assessing...	Yes a one stop shop for the initial assessment and ongoing management would be ideal, if investigations could be done concurrently and where possible in the same appointment. People want investigations but they need support to manage their health alongside this. Identify a key professional responsible for the coordination of each individual's care and selecting this professional. Consider implementing one-stop helplines which people can

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				contact with general queries about their Long Covid experience to get signposting/access to additional support in a timely manner. What is the rationale for highlighting "with expertise in treating fatigue and respiratory symptoms" rather than - say - cognitive, cardiac or dysautonomia symptoms, which are also commonly reported? it is now widely recognised in the literature that long covid is far more than a respiratory disease with multiorgan and mutli system effects. Physician-led medical assessments and diagnostics should be prioritised initially, but with concurrent allied health professional input including physiotherapy, occupational therapy, dieticians etc to advise on management. The lead clinician should be a doctor who is well versed in multisystemic disorders, with cross-discipline knowledge.
Long Covid SOS	Guideline	Service Org	8.2 [SUPPORTING REMARK ADDED] Additional expertise should be provided according to the person's needs...	"Services should be led by a doctor" yet the core services described don't include any medical (non psych) specialties. Many from the 'additional expertise' list appear key to the care of those with Long Covid and should, ideally, be part of the Multi-Disciplinary team
UK Doctors Long Covid	Guideline	Service Org	8.2 [SUPPORTING REMARK ADDED] Additional expertise should be provided according to the person's needs...	A doctor with relevant expertise in evaluating the symptoms (eg rehab physician, general practitioner or physician with special interest) should always be included in the core team and arguably should lead the core team. The importance of having a named clinician taking the overall lead to ensure coordination of care cannot be overstated. We suggest putting rehab medicine at the top of the list and highlighting that the preference would be for the rehab clinician (or other clinician) to oversee the service and liaise directly with primary care. Please include vocational rehabilitation in the list for supporting people in returning to work.
NHS England	Guideline	Service Org	8.2 [SUPPORTING REMARK ADDED] Additional expertise	A helpful addition

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			should be provided according to the person's needs...	
Long COVID Scotland Action Group	Guideline	Service Org	8.2 [SUPPORTING REMARK ADDED] Additional expertise should be provided according to the person's needs...	A more comprehensive list of disciplines is necessary to avoid suggesting that only the ones mentioned are important.
British Dietetic Association	Guideline	Service Org	8.2 [SUPPORTING REMARK ADDED] Additional expertise should be provided according to the person's needs...	Good to see a more comprehensive list of health and care professionals included. Nutritional care is not only about symptom management, rehabilitation is likely to be most effective where nutrition is optimised. People identified for rehab should be advised of this and directed to trustworthy resources (See Wojzischke et al., 2020. Nutritional status and functionality in geriatric rehabilitation patients: a systematic review and meta-analysis and van Wijngaarden et al., 2020. Effects of nutritional interventions on nutritional and functional outcomes in geriatric rehabilitation patients: A systematic review and meta-analysis.) As advised by expert testimony, reliable sources of dietary advice and support should be made clear.
Royal College of Speech and Language Therapists (RCSLT)	Guideline	Service Org	8.2 [SUPPORTING REMARK ADDED] Additional expertise should be provided according to the person's needs...	Rationale We appreciate that the role of the speech and language therapist can be misunderstood, but the list of common symptoms provided by NICE do indeed capture many areas where a speech and language therapist will provide intervention and support. Speech and language therapists have the skills, knowledge and experience to work with people with chronic cough and breathlessness (Freeman-Sanderson et al, 2021). Making a secure diagnosis is vital and requires MDT management. Treatment includes therapy interventions, which are often multi-modal, and usually provided by both speech and language therapists and physiotherapists (GPICS 2019), (Patterson et al 2020). The addition of speech and language therapists to the core team is backed up by evidence from

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				Blomberg et al. (2021) which shows that the most common symptoms of mental fatigue were difficulties finding words (23%), difficulties concentrating (19%) and memory problems (18%), which links with cognitive impairment. These are key roles and domains for speech and language therapy. The common symptom list includes 'sore throat'. Here, people with long-COVID are describing laryngeal hypersensitivity/lump in the throat with concomitant hoarse voice +/- reflux changes. Numerous studies reference very specific throat effects, indicating involvement from ENT professionals/speech and language therapists. Failure to include speech and language therapists means that people are not screened for voice, swallowing and upper airway problems. These difficulties have a significant impact on quality as well as day-to-day functioning and ability to stay in work or education. Recommendation Given the heterogeneous nature of long-COVID, and the growing evidence base, it would make sense to reword this sentence, for clarity, to say "the core team could include, but not be limited to: physio, OT, rehab medicine, clinical psychology and psychiatry, rheumatology, neurology rehabilitation, cardiology, paediatrics, dietetics, speech and language therapy, nursing, pharmacy and support to return to education or work".
Long Covid Support	Guideline	Service Org	8.2 [SUPPORTING REMARK ADDED] Additional expertise should be provided according to the person's needs...	Recognise that perhaps the key professional for someone may be the health professional most relevant to their presenting needs. Consider here also the role of expert patients and groups such as Long Covid Support who can share skills from a lived experience perspective. This is also relevant to the next recommendation on sharing knowledge, skills,ie include patient groups in these service discussions Also learn from pioneering services around the country and facilitate rapid sharing of knowledge and resources both on what works well and what doesn't. Learn from rather than repeat the mistakes of others.
Patient-Led Research Collaborative	Guideline	Service Org	8.2 [SUPPORTING REMARK ADDED] Additional expertise should be provided	Recommend adding social work/case management here, as social determinants to health and financial/legal barriers can be significant for this population, and are just as necessary as PT, OT, rehabilitation and other medical services.

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			according to the person's needs...	
British Thoracic Society	Guideline	Service Org	8.2 [SUPPORTING REMARK ADDED] Additional expertise should be provided according to the person's needs...	Regarding the statement on 'share knowledge ….' 'breathlessness training' is very non-specific and the 1 min sit to stand rather limited Suggest keeping the statement about sharing knowledge and either improve the breadth and detail of the examples or remove
The National Guideline Centre (ME/CFS guideline committee)	Guideline	Service Org	8.2 [SUPPORTING REMARK ADDED] Additional expertise should be provided according to the person's needs...	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 the possibility of confusion between post-COVID-19 syndrome and ME/CFS. For people who have symptoms consistent with ME/CFS, the recommendations in the draft ME/CFS guideline should be considered when considering the management of fatigue. We also suggest that 'managing fatigue' is a better term than treating fatigue.
The National Guideline Centre (ME/CFS guideline committee)	Guideline	Service Org	8.2 [SUPPORTING REMARK ADDED] Additional expertise should be provided according to the person's needs...	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 the possibility of confusion between post-COVID-19 syndrome and ME/CFS. For people who have symptoms consistent with ME/CFS, the recommendations in the draft ME/CFS guideline should be considered when considering the management of fatigue. We also suggest that 'managing fatigue' is a better term than treating fatigue.
Department of Health and Social Care (DHSC)	Guideline	Service Org	8.2 [SUPPORTING REMARK ADDED] Additional expertise should be provided according to the person's needs...	The setting in which the patient is evaluated in plays a key part. Assessment in an acute setting/hospital setting may further deteriorate symptoms such as fatigue and mental health issues.

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Long Covid Wales	Guideline	Service Org	8.2 [SUPPORTING REMARK ADDED] Additional expertise should be provided according to the person's needs...	This too is important, and is so much more efficiently provided where Consultant-to-Consultant referrals can be made after initial referral to a medical Consultant-led dedicated Long COVID clinic. Hence the importance of the previous comment regarding 8.1.
Asthma UK and the British Lung Foundation	Guideline	Service Org	8.2 [SUPPORTING REMARK ADDED] Additional expertise should be provided according to the person's needs...	We agree with this recommendation.
NHSEI - Specialised commissioning	Guideline		8.2 [SUPPORTING REMARK ADDED] Additional expertise should be provided according to the person's needs...	And respiratory medicine ! (especially if the assessment service is not run by a respiratory physician)
Long Covid Wales	Guideline	Service Org	8.4 [UPDATED] Agree local, integrated referral pathways…	Agreed, but such pathways should be easy, not obstructive and paved with obstructions - ignorant persons who demand e.g. a positive PCR test etc.
NHS England	Guideline	Service Org	8.4 [UPDATED] Agree local, integrated referral pathways…	Consider multi-agency support, in particular utilising third sector and community support.
Long Covid SOS	Guideline	Service Org	8.4 [UPDATED] Agree local, integrated referral pathways…	It is better for patients to be referred to other specialists directly from the multidisciplinary assessment clinics rather than requiring them to go back to their GPs. All referrals should have contact information so that patient expectations around referral times can be

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				managed. There is evidence that some contact numbers in referrals do not have a line of communication with the services stated. The patient should be able to follow up on appointments and decisions made. Information should also be shared in an accessible format with the patient who is the one left navigating, with little resources, any discontinuity of care. Multiple professionals asking a patient to reiterate their story puts added responsibility onto those needing help and support.
Royal College of Occupational Therapists	Guideline	Service Org	8.4 [UPDATED] Agree local, integrated referral pathways…	Local authorities and third sector organisations should also be added to this list. They are involved in the support of people with post COVID-19 syndrome in various ways, e.g. local authorities – environmental assessment and provision of equipment and adaptations; care needs assessments. Third sector organisations – social support; social prescribing; supported self-management. Additional training and support may be needed by local teams.
UK Doctors Long Covid	Guideline	Service Org	8.4 [UPDATED] Agree local, integrated referral pathways…	Please emphasise the importance of a named clinician as the central coordinating point for the care received from different professionals. Please provide link to the NHSE guidance on the design of a Long Covid clinic/service and consider providing a flow diagram for the optimal flow of a patient through different services.
Long COVID Scotland Action Group	Guideline	Service Org	8.4 [UPDATED] Agree local, integrated referral pathways…	This is important and I agree with the rationale, but how are GPs able to do this? Is there any support for them?
Asthma UK and the British Lung Foundation	Guideline	Service Org	8.4 [UPDATED] Agree local, integrated referral pathways…	We agree with this recommendation.
NHS England	Guideline	Service Org	8.4 [UPDATED] Agree local, integrated referral pathways…	Where is the patient experience evidence presented?

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Long Covid Support	Guideline	Service Org	8.4 [UPDATED] Agree local, integrated referral pathways…	Where local services are not available ensure that people don't miss out on key support. Look into process to refer them out of area if needed. Many people have assessments at long covid clinics and are then discharged from the service back to primary care despite ongoing symptoms. how then will these people find out about new interventions and treatments emerging from knowledge sharing or research. Rather than discharging, it should be considered to keep people within the service with 3 monthly quick reviews to seek updates on their progress and on potentially new tests, treatments/ interventions. I appreciate this is extra burden, but Many people are finding accessing GP support difficult especially with the com[lexity of long covid and lack of specialist GP knowledge in this new and complex syndrome. Consider if it is in fact more efficient for a quick review with a long covid specialist healthcare worker who is up to date with new research than a GP who is already overburdened and unspecialised. e.g. from the USA CDC long covid guidance "Continuing follow-up over the course of illness, with considerations of broadening the testing and management approach over time if symptoms do not improve or resolve, while remaining transparent that there is much more to learn about post-COVID conditions."....."Knowledge of post-COVID conditions is likely to change rapidly with ongoing research. Healthcare professionals and patients should continue to check for updates on evolving guidance for post-COVID conditions."
NHSEI - Specialised commissioning	Guideline		8.4 [UPDATED] Agree local, integrated referral pathways…	ok
Long Covid Wales	Guideline	Symptoms	[UPDATED] Neurological symptoms	"Difficulty with words" / Specific Lexical Retrieval Difficulty should be given as a symptom, which combined with brain fog / slowed mentation amounts to a disability in itself. Hence, conversation with and comprehension of healthcare practititioners and those around someone suffering will be impaired, as will the ability to use apps, let alone electronic devices, or gain benefit from leaflets. Speaking with a human being, preferably on person, is much to be preferred.

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Long COVID Scotland Action Group	Guideline	Symptoms	[UPDATED] Neurological symptoms	• What about dysautonomia symptoms, including orthostatic intolerance? These are very common symptoms. • What about PANS in children? – caused by neuroinflammation and not well known about; it's important for doctors to have sight of this condition.
Long COVID Physio	Guideline	Symptoms	[UPDATED] Neurological symptoms	In generalised symptoms it is critical to include post-exertional symptom exacerbation based on: - Literature on common symptoms including post-exertional symptom exacerbation; https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370(21)00299-6/fulltext https://www.medrxiv.org/content/10.1101/2021.06.11.21258564v1.full.pdf - Literature on aetiology and mechanisms of exercise intolerance; https://journal.chestnet.org/article/S0012-3692(21)03635-7/fulltext - CDC guidelines including post-exertional symptom exacerbation; https://www.cdc.gov/coronavirus/2019-ncov/hcp/clinical-care/post-covid-conditions.html - Rehabilitation briefing papers, standards and guidelines specifically referencing post-exertional symptom exacerbation; https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-2021_0.pdf https://www.albertahealthservices.ca/assets/info/ppih/if-ppih-covid-19-rehab-allied-health-practice-considerations-post-covid.pdf#page38 https://physiotherapy.ca/sites/default/files/site_images/Advocacy/long_covid_en-final-rev2.pdf https://www.csp.org.uk/system/files/publication_files/001745_Community%20Rehab%20Standards_A4_V7.pdf https://www.csp.org.uk/system/files/publication_files/001745_Hospital%20Standards_A4_V10_3.pdf https://apps.who.int/iris/bitstream/handle/10665/344472/WHO-EURO-2021-855-40590-59892-eng.pdf?sequence=1&isAllowed=y We believe that communities of people living with and affected by Long COVID have been consistently clear that post-exertional symptom exacerbation (PESE) (also known as post-exertional malaise) should be included in the list of common symptoms. If this is not included, it should be highlighted in the rationale along with other symptoms that were not included in the list, with a provided explanation as to why this symptom has not been included. Furthermore, there is no

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				reference to autonomic dysfunction (such as orthostatic intolerance or POTS) which is increasingly common and should be included as reference din the CDCs inclusion of "lightheadedness" https://www.cdc.gov/coronavirus/2019-ncov/hcp/clinical-care/post-covid-conditions.html Please see also https://pubmed.ncbi.nlm.nih.gov/33740207/. The expert testimony also highlighted how common this was and the importance for recognition in their service delivery model (Gp Capt Edward Nicol QHS).
Sheffield ME and Fibromyalgia Group (inc long COVID)	Guideline	Symptoms	[UPDATED] Neurological symptoms	It is crucial that post-exertional malaise is recognised by health care professionals and patients as a symptom. This is so debilitating for patients. It may be better under 'generalised symptoms'.
Long Covid Support	Guideline	Symptoms	[UPDATED] Neurological symptoms	NOTE no chance to comment on other categories so included them here: Neurological: Include dysautonomia as it leads to e.g. breathing pattern disorders,heart rate disorder. Unusual sensations, specifically listed in CDC guidelines as parasthesia e.g. of burning/prickling sensations/fizzing Poor temperature control e.g. hot and cold flushes not related to menopause. Dizziness could be expanded to using PoTS/IST- more detail needed elsewhere about when/how to investigate. Consider that fatigue may not just be a generalised symptom but may be neurological. Patient groups are often preferring to use the term energy limitation to reflect this. Refer on to Occupational Therapy/Psychology for more in depth cognitive assessment if required. Consider including migraine as well as headaches as it is quite different and commonly reported in patient groups. Generalised systems: New onset allergies and intolerances including MAST cell disorder as highlighted in USA CDC guidelines and widely reported in support groups. Many people are finding antihistamines such as H1 and H2 blockers very helpful as well as different exclusion diets. These are being investigated by funded research. USA CDC includes as a symptom Post Exertional Malaise/poor indurance. This is critical to include specifically as a symptom as its a major patient safety risk when exercise is prescribed or advised and does harm to patient.

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				USA CDC includes “impaired daily function and mobility”, this could be considered an outcome but CDC lists and a symptom which is helpful in recognising this in patients. Respiratory: Exacerbation of pre-existing lung conditions, e.g. asthma and COPD that may or may not respond to treatments for that condition. Respiratory:: USA CDC guidance also considers “respiratory effort” Cardiovascular: consider including tachycardia as included in USA CDC guidelines and commonly reported by patient groups, high heart rate obvious symptom of pericarditis often noted in covid-19 patients, beta blockers commonly prescribed to long covid patients for this Menstrual disturbances should not be excluded on the basis of lack of ‘evidence’, since they are commonly reported in patient groups and the lack of interest or funding to ‘research’ this does not demean its prevalence or significance. Patient Led Research Collaborative reported the prevalence of this as do ZOE app results.
UK Doctors Long Covid	Guideline	Symptoms	[UPDATED] Neurological symptoms	Please include neuropathic pain, dizziness (vertigo), and include ‘executive functions’ in relation to cognitive dysfunction
Patient-Led Research Collaborative	Guideline	Symptoms	[UPDATED] Neurological symptoms	Post-exertional malaise and menstrual symptoms must be added somewhere in this list. We recommend the committee consider adding occipital neuralgia, trigeminal neuralgia, tremors, and hallucinations. See https://doi.org/10.1016/j.eclinm.2021.101019 and https://patientresearchcovid19.com/resources-for-long-covid-researchers/
Royal College of Speech and Language Therapists (RCSLT)	Guideline	Symptoms	[UPDATED] Neurological symptoms	We appreciate that the role of the speech and language therapist can be unknown or misunderstood, but the list of common symptoms provided by NICE do indeed capture many areas where a speech and language therapist will provide intervention and support. These are areas where we have evidence of their prevalence in Long COVID (as given previously), and evidence of the efficacy of SLTs in supporting patients with such symptoms. This includes: breathlessness, cough, fatigue, cognitive impairment (also, cognitive communication impairment), muscle weakness/muscle pain, psychological/psychiatric symptoms, sore throat, loss of taste/smell. Research studies quote changes in voice (Domingo 2021) (Michelen 2021). Davis et al found that 28% of overall participants experienced changes in the voice. Following post ICU 12 WEEKS

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				REVIEW CLINICS in Belfast trust at least 40% of all individuals assessed experienced dysphonia or globus or both. Further evidence: 1. Davis, H. E. et al. (2021) Characterizing Long-COVID in an International Cohort: 7 Months of Symptoms and Their Impact. EClinicalMedicine. DOI: https://doi.org/10.1016/j.eclinm.2021.101019 2. Seeßle, J. et al (2021) Persistent symptoms in adult patients one year after COVID-19: a prospective cohort study. Clinical Infectious Diseases, ciab611, DOI: https://doi.org/10.1093/cid/ciab611 3. Halpin et al. (2020) Postdischarge symptoms and rehabilitation needs in survivors of COVID-19 infection: A cross-sectional evaluation. Journal of Medical Virology, 93 (2), 1013-1022. DOI: 10.1002/jmv.26368
#MEAction UK	Guideline	Symptoms	[UPDATED] Neurological symptoms	We remain concerned that post-exertional malaise is not mentioned in this guideline, despite it being amongst the most commonly reported symptoms six months post Covid-19 according to Davis, H.E. et al.: https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370(21)00299-6/fulltext#%20 This guideline overall does a disservice to patients by choosing to avoid this important area instead of confronting it. Clinicians following this guideline may lack necessary knowledge of post-exertional malaise, leading them to underestimate or ignore the impact of post-exertional malaise on management and rehabilitation and ultimately enable to ongoing harm of these patients. Clinicians should be directed to investigate whether a patient is experiencing post-exertional malaise post-Covid-19 and consider a diagnosis of coronavirus-triggered ME/CFS if this is present (taking into account any tests and other symptoms the patient is experiencing).
Patient-Led Research Collaborative	Guideline	Symptoms	[UPDATED] Gastrointestinal symptoms	Add acid reflux. Also see https://doi.org/10.1016/j.eclinm.2021.101019 and https://patientresearchcovid19.com/resources-for-long-covid-researchers/
Long COVID Scotland Action Group	Guideline	Symptoms	[UPDATED] Gastrointestinal symptoms	Dysautonomia symptoms like acid reflux are also common as are persistent bowel disturbances.

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Long Covid Wales	Guideline	Symptoms	[UPDATED] Gastrointestinal symptoms	Hyperacidity/heartburn/indigestion/acid reflux should be added, and, incidentally, is one of the many symptoms alleviated by treatment with an H2-blocker. Newly presenting or exacerbation of existing irritable bowel symptom is also seen.
Long Covid Support	Guideline	Symptoms	[UPDATED] Gastrointestinal symptoms	Increased sensitivity to certain food/drink/substances, e.g. caffeine, alcohol may be linked to Mast Cell disorder and histamine. Anti-histamines and mast cell stabilisers are treatments starting to be used - see testimonial by Elizabeth Whittaker. See USA CDC guidelines which recognise increase in allergies and intolerances and specifically mentions MAST cell disorder. Many patients report acid reflux, LPR, and GLOBUS type symptoms (swallowing difficulties). it could be worth mentioning these as they can be easily recognised and treated and may fit in with the increased food sensitivities and benefit from proton pump inhibitors, H2 blockers etc.
UK Doctors Long Covid	Guideline	Symptoms	[UPDATED] Gastrointestinal symptoms	Please add polyuria/polydipsia either here or in a separate endocrine option (symptoms of diabetes) Please add tachycardia to cardiovascular symptoms
Public Health Scotland	Guideline	Symptoms	[UPDATED] Gastrointestinal symptoms	Weight loss? Always a red flag when unintentional– is there a worry this could be labelled as post-COVID when actually needs investigation (especially given current delayed diagnosis of neoplasia)?
Patient-Led Research Collaborative	Guideline	Symptoms	[UPDATED] Psychological/psychiatric symptoms	Add suicidality and changes in mood. See https://doi.org/10.1016/j.eclinm.2021.101019 and https://patientresearchcovid19.com/resources-for-long-covid-researchers/
Long Covid Support	Guideline	Symptoms	[UPDATED] Psychological/psychiatric symptoms	Anxiety can commonly result from dysautonomia and the chronic sympathetic nervous system response. In children (and potentially adults too), be aware of PANS/PANDAS where rapid onset psychiatric symptoms may occur, e.g. tics, hallucinations, OCD, psychosis, mood disorders, anxiety. (Ifif recognised this can be treated with antibiotics). Good to have added PTSD, thanks. Can you also add “mood changes” as listed in the USA CDC guidelines.

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Long COVID Scotland Action Group	Guideline	Symptoms	[UPDATED] Psychological/psychiatric symptoms	Due to the risk of medical bias (psychologising), mental health symptoms should be listed last, with a flag that nervous system issues, MCAS and nutritional deficiencies could play a role in dysautonomia.
Royal College of Paediatrics and Child Health	Guideline	Symptoms	[UPDATED] Psychological/psychiatric symptoms	Suggest low mood and anxiety rather than depression or add both.
NHSEI - Specialised commissioning	Guideline		[UPDATED] Psychological/psychiatric symptoms	Sleep disturbance should be here rather than neurology
Long COVID Scotland Action Group	Guideline	Symptoms	[UPDATED] Ear, nose and throat symptoms	• It's worth noting tinnitus can be pulsatile in nature. • In addition, include swallowing difficulties – this is a common symptom.As is persistent sore throat. • Also include feelings of pressure in the head.
Royal College of General Practitioners	Guideline	Symptoms	[UPDATED] Ear, nose and throat symptoms	Can the committee revisit the term 'dizziness' and consider replacing this with or adding in 'vertigo' as it is more clinically appropriate and includes a wider description.
Patient-Led Research Collaborative	Guideline	Symptoms	[UPDATED] Ear, nose and throat symptoms	Eye symptoms should be added here or in some category. Change loss of taste and smell to changes to taste and smell, and consider moving to neurological. See https://doi.org/10.1016/j.eclinm.2021.101019 and https://patientresearchcovid19.com/resources-for-long-covid-researchers/
Long Covid Support	Guideline	Symptoms	[UPDATED] Ear, nose and throat symptoms	List loss of taste and smell within neurological symptoms?, Amend wording to say 'changes to taste and/or smell', since phantom smells and taste are common. Vocal cord dysfunction should also be considered, many people struggling with vocal problems, and benefiting from Speech and Language Therapy, which is offered as part of post covid clinics in some cases.
Royal College of Speech and	Guideline	Symptoms	[UPDATED] Ear, nose and throat symptoms	Mouth ulcers and Covid tongue (Nuno-Gonzalez et al. 2020) could be added to this symptom list as many patients from Long-COVID MDT rehab clinic have presented with

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Language Therapists (RCSLT)				this. The RCSLT recommends adding swallowing difficulties, changes to voice and throat irritation. In a 12-week MDT post-covid syndrome pilot (unpublished), 21% of patients referred into the service reported voice, swallowing or upper airway symptoms. In context, 25% also reporting psychological symptoms, 58% respiratory symptoms, 62% fatigue and cognitive symptoms. In conclusion, swallowing/voice/upper airway symptoms were similar in numbers and therefore should be added to the list of 'common symptoms'. In light of common otolaryngological symptoms (see Naunheim et al. 2020 on Laryngeal Complications of COVID19), including but not limited to anosmia, dysgeusia, dysphagia (see e.g. Grilli, Giancaspro et al. 2021), dysphonia (see e.g. Chaudhry, McGinnis et al. 2021), odynophagia, upper airway disorders (see e.g. Piazza et al., 2021), an appropriate ENT healthcare professional such as a AHP/SLT/medical representative is key. (see e.g. Lechien, Chiesa-Estomba et al. 2020, Neevel, Smith et al. 2021, Piazza et al. 2021) The term sore throat may be potentially misleading – for many patients what they are describing is a laryngeal hypersensitivity/lump in the throat type pattern, with concomitant hoarse voice +/- reflux changes (see e.g. Boggiano et al. 2021). Sore throat has been reported in the literature as an all-encompassing term but there are several studies that reference very specific throat effects that warrant the involvement of specific ENT/Speech and Language Therapy professionals (see e.g. Rouhani, Clunie et al. 2020). As evidence of this potential diagnostic overshadowing/ under-reporting/ undervalued role, in a recent letter to the editor of AJM international medical journal, Taylor-Robinson (2021) writes: "I should like to draw wider attention to the problem and make a recommendation that speech and language therapy (SLT) is made more easily available to those suffering dysphonia as a result of COVID-19". References: Piazza C, Filauro M, Dikkers FG, Nouraei SR, Sandu K, Sittel C, Amin MR, Campos G, Eckel HE, Peretti G. Long-term intubation and high rate of tracheostomy in COVID-19 patients might determine an unprecedented increase of airway stenoses: a call to action from the European Laryngological Society. European Archives of Oto-Rhino-Laryngology. 2021 Jan;278:1-7. Boggiano S, Williams T, Gill SE, Alexander PD, Khwaja S, Wallace S, McGrath BA. Multidisciplinary management of laryngeal pathology

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				identified in patients with COVID-19 following trans-laryngeal intubation and tracheostomy. Journal of the Intensive Care Society. 2021:17511437211034699.
UK Doctors Long Covid	Guideline	Symptoms	[UPDATED] Ear, nose and throat symptoms	Please include vertigo alongside dizziness
Royal College of Paediatrics and Child Health	Guideline	Symptoms	[UPDATED] Dermatological symptoms	Add covid toes and covid fingers.
Patient-Led Research Collaborative	Guideline	Symptoms	[UPDATED] Dermatological symptoms	Add itchy skin, petechiae, COVID Toes, peeling skin, brittle/discolored nail. See https://doi.org/10.1016/j.eclinm.2021.101019 and https://patientresearchcovid19.com/resources-for-long-covid-researchers/
Royal College of General Practitioners	Guideline	Symptoms	[UPDATED] Dermatological symptoms	Can the committee consider adding “itch” to the symptoms list or stating “rash, with or without itching”
Long Covid Support	Guideline	Symptoms	[UPDATED] Dermatological symptoms	Facial flushing
Long COVID Scotland Action Group	Guideline	Symptoms	[UPDATED] Dermatological symptoms	There could be more elaboration of these symptoms. Most recently skin rashes and allergic reactions have become more common - reactions to hair dye should be noted. A reference could be made to MCAS, which is linked to Long Covid
Long Covid Support	Guideline	Symptoms	[NEW] Comment on symptoms that are less common in children and young people	As well as identifying which symptoms from the adult symptom list are less common in children, it is surely equally, if not more important to identify which symptoms are more common in children. Include seizures, tics and other neurological conditions that can present in children. I would debate the fact that palpitations and variations in heart rate are less common in children based on the experiences within the Long Covid Kids group. It should also be noted that young children may have trouble describing the problems they are experiencing, particularly given the unusual nature of some symptoms experienced in adults and children, e.g. sensation of every cell vibrating/buzzing

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UK Doctors Long Covid	Guideline	Symptoms	[NEW] Comment on symptoms that are less common in children and young people	Is this comment really needed? It diminishes Long Covid in children if it is not counter balanced with a list of the symptoms more commonly experienced by children affected by Long Covid. If there is not sufficient evidence for the latter, then there is not sufficient evidence to make this statement. Please remove or balance with a list of symptoms more commonly seen in children.
Long COVID Physio	Guideline	Symptoms	[NEW] Comment on symptoms that are less common in children and young people	It would be worth noting that "variations in heart rate" should be included in the common cardiovascular symptoms list, not just in the symptoms less commonly seen in children. Variations in heart rate are specific to autonomic nervous system dysfunction eg: dysautonimia: https://www.cdc.gov/coronavirus/2019-ncov/hcp/clinical-care/post-covid-conditions.html https://internal-journal.frontiersin.org/articles/10.3389/fneur.2021.624968/full https://link.springer.com/article/10.1007/s12026-021-09185-5?fbclid=IwAR054Og-JQV1WLtLUiM3tt1dGDzg41UhSy6yMd5ht_AQjXjm9eL6vKQoeq8 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7685310/ https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7976723/
Long COVID Scotland Action Group	Guideline	Symptoms	[NEW] Comment on symptoms that are less common in children and young people	Noting what is less common leads to bias; it's likely to be heard as 'this never happens' – please ensure this bias is mitigated.
Long Covid SOS	Guideline	Symptoms	[NEW] Comment on symptoms that are less common in children and young people	Rather than listing less common symptoms in children, it would be useful to list the symptoms that children are more likely to present.
Royal College of Occupational Therapists	Guideline	Symptoms	[NEW] Comment on symptoms that are less common in children and young people	This is likely to help practitioners and caregivers identify red flags for referral.

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Royal College of Paediatrics and Child Health	Guideline	Symptoms	[NEW] Comment on symptoms that are less common in children and young people	This is repetition from earlier in the document – suggest including only once or Remove as confusing - see before about considering a greater breadth in CYP.
Royal College of Speech and Language Therapists (RCSLT)	Guideline	Symptoms	[NEW] Comment on symptoms that are less common in children and young people	Voice problems have been reported in secondary age children, albeit in smaller numbers than some of the more known physical symptoms, which would warrant their inclusion, these include hoarse voice, dysphonia, and speech and language difficulties. References (Molteni 2021), (Penner 2021).
Royal College of General Practitioners	Guideline	Symptoms	[NEW] Comment on symptoms that are less common in children and young people	We believe this section would benefit from a research recommendation that looks specifically at the prevalence and experiences of the long-term effects of COVID-19 in children, as well as investigating the effectiveness of interventions. Please note. We would also recommend an additional research recommendation to look into the symptoms of headache in Post COVID-19 syndrome which is very common and not understood with no clear treatment pathway identified. The list of paediatric symptoms is new, yet no comment was asked for. We note that this list does not align with the list of common symptoms and we would recommend the 2 align using the same terminology. For example: Shortness of breath / breathlessness, persistent cough/cough, chest pain/ pain on breathing, palpitations/ variation in heart If it is not listed as a common symptoms such as “variation in heart rate and “pain on breathing” we do not understand why its listed as “less common” in children. Can the committee consider removing them o the 2 lists align? Alternatively, adding variation in heart rate and pain on breathing (which is covered by chest pain already) to the list of common symptoms if indeed this is a commonly described symptom?
Patient-Led Research Collaborative	Guideline	Symptoms	[NEW] Comment on symptoms that are less common in children and young people	What is more common would be more helpful.

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Long COVID Scotland Action Group	Guideline	ResearchRec	[DELETED] Risk factors for post COVID-19 syndrome	Cannot comment without seeing full text
NHS England	Guideline	ResearchRec	[DELETED] Risk factors for post COVID-19 syndrome	How can a comment be made on risk factors that have been deleted from the guideline and which aren't represented fully in this document?
Asthma UK and the British Lung Foundation	Guideline	ResearchRec	[DELETED] Risk factors for post COVID-19 syndrome	It is vital that we continue to understand the impact of Long COVID on specific groups, to support the creation of targeted interventions. Reviewing findings from the Post Hospitalisation COVID-19 study (PHOSP-COVID) may be helpful in achieving this.
Long Covid Support	Guideline	ResearchRec	[DELETED] Risk factors for post COVID-19 syndrome	This question should not be deleted. It's important to understand what factors may predispose an individual to develop long covid, especially as there is little understanding of these and of what impact early intervention could have on the disease progression. Impact of pre-existing conditions should be investigated, such as asthma which has been reported as a risk factor.
Long COVID Physio	Guideline	ResearchRec	[DELETED] Risk factors for post COVID-19 syndrome	This should include the risk factors of disability among people living with Long COVID
NHSEI - Specialised commissioning	Guideline		[DELETED] Risk factors for post COVID-19 syndrome	Why delete? If we knew it would offer some insight into the condition
Long COVID Scotland Action Group	Guideline	ResearchRec	[UPDATED] Prevalence of post-COVID-19 syndrome	• The question could also be expanded to include other unrepresented groups. • The question needs to consider the fact that ONS stats were not informed by lived experience.
Long Covid Wales	Guideline	ResearchRec	[UPDATED] Prevalence of post-COVID-19 syndrome	The flip side of this is how common are side-effects of vaccination in those who have Long COVID? This is an important question for those suffering from Long COVID.

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University of Leicester	Guideline	ResearchRec	[UPDATED] Prevalence of post-COVID-19 syndrome	The number of included papers to build the evidence is small. Some have been excluded or paused until a later iteration without clarity for the rationale. Some studies on prevalence particularly in the post-hospitalisation setting have not been considered. the Whittaker et al pre-print is used as part of the evidence base. this shows stark differences between those hospitalised versus managed in the community with post-COVID syndrome. this study focusses on an early time period after the incident infection. There are other studies that support the view of this difference. Highlighting this difference and making a research question would be valuable. For example, why are there these differences, does it reflect different case mix of those hospitalised a different host-response to the infection or possibly different long-term responses. If this is the case it would have implications on different underlying pathophysiological mechanisms and consequences for health care provision and possible interventions.
Long COVID Physio	Guideline	ResearchRec	[UPDATED] Prevalence of post-COVID-19 syndrome	This should include the prevalence of disability among people living with Long COVID
Asthma UK and the British Lung Foundation	Guideline	ResearchRec	[UPDATED] Prevalence of post-COVID-19 syndrome	We agree with the need for further research into Long COVID prevalence in people who have had a single, double or booster dose of COVID-19 vaccinations. It would helpful if NICE reviewed emerging research examining the impact of vaccinations on Long COVID symptoms such as the following study: 8bd4fe_a338597f76bf4279a851a7a4cb0e0a74.pdf (filesusr.com)
#MEAction UK	Guideline	ResearchRec	[UPDATED] Prevalence of post-COVID-19 syndrome	We support this updated recommendation.
Long Covid Support	Guideline	ResearchRec	[UPDATED] Prevalence of post-COVID-19 syndrome	What is the prevalence but also seeing if we can extrapolate out reasons, genetic susceptibility, social factors, behaviour etc. Need to aim to identify causes not just correlation. Need more research into gendered, sex based differences in post-COVID-19 syndrome - e.g. impact of hormones, menstrual cycle, erectile dysfunction etc.

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NHSEI - Specialised commissioning	Guideline		[UPDATED] Prevalence of post-COVID-19 syndrome	agree
Long COVID Scotland Action Group	Guideline	ResearchRec	[NEW] What pathophysiological mechanism(s) underlie the most common presentations of post-COVID-19 syndrome?	• Suggest using examples of common presentations that aren't as stigmatised in order to challenge the current narrative that LC is just tiredness.
University of Leicester	Guideline	ResearchRec	[NEW] What pathophysiological mechanism(s) underlie the most common presentations of post-COVID-19 syndrome?	as above
Long Covid SOS	Guideline	ResearchRec	[NEW] What pathophysiological mechanism(s) underlie the most common presentations of post-COVID-19 syndrome?	It is a continued concern that the separation between acute, ongoing and post covid means that the progression between these stages are looked at in isolation and not as a continuum. Idealistically, we would be in a situation where preventative treatments such as anti-virals in the acute stage could ensure the lack of progression to Long Covid and not solely be measured in prevention of hospitalisation and death. Whilst we understand the need to separate acute and post, with regards to provision of clear clinical guidelines, as a patient advocacy organisation it appears that the separation of cause from effect may lead to evidence being missed and does not take into account reality. There should be research that focusses on potential interventions to prevent the condition developing after acute Covid-19. Research should also look into whether there are any biological reasons (ie hormones etc) why Long Covid appears to be more prevalent in women. While there is

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				potentially a reporting bias for men, it should be recognised that this is an assumption and there have been historical discrepancies in research into women's health.
Long Covid Wales	Guideline	ResearchRec	[NEW] What pathophysiological mechanism(s) underlie the most common presentations of post-COVID-19 syndrome?	It would appear that disordered coagulation in particular is an important component of the pathophysiology of Long COVID, which relates back to the comment on prognostic markers and D-dimer testing.
Royal College of Speech and Language Therapists (RCSLT)	Guideline	ResearchRec	[NEW] What pathophysiological mechanism(s) underlie the most common presentations of post-COVID-19 syndrome?	The RCSLT recommends including 'otolaryngological symptoms' for investigation regarding pathophysiological mechanisms.
Long COVID Physio	Guideline	ResearchRec	[NEW] What pathophysiological mechanism(s) underlie the most common presentations of post-COVID-19 syndrome?	This should include pathophysiological mechanisms that underline exercise intolerance among people living with Long COVID experiencing the symptom of post-exertional symptom exacerbation.
Asthma UK and the British Lung Foundation	Guideline	ResearchRec	[NEW] What pathophysiological mechanism(s) underlie the most common presentations of post-COVID-19 syndrome?	We do not have any comments related to this recommendation.

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#MEAction UK	Guideline	ResearchRec	[NEW] What pathophysiological mechanism(s) underlie the most common presentations of post-COVID-19 syndrome?	We strongly support increased biomedical research into this illness.
Long Covid Support	Guideline	ResearchRec	[NEW] What pathophysiological mechanism(s) underlie the most common presentations of post-COVID-19 syndrome?	What pathophysiological mechanisms … It would be useful to co-produce some of this research and learn from other conditions, e.g. neurology (MS/Stroke), ME/CFS, Dysautonomia, mast cell activation, PANS/PANDAS (e.g. is breathlessness respiratory or cardiac related). And treatments used for these, fatigue management education, adaptive pacing, heart rate pacing. Ivabradine, anti-histamine, antibiotics etc. Increasingly there is evidence that microthrombi are the end result of the pathological process, this should be an urgent focus especially in view of anecdotal reports of success with apheresis.references Acanfora et al “The Cross-Talk between Thrombosis and Inflammatory Storm in Acute and Long-COVID-19: Therapeutic Targets and Clinical Cases”; Pretorius et al “Persistent clotting protein pathology in Long COVID/Post-Acute Sequelae of COVID-19 (PASC) is accompanied by increased levels of antiplasmin”; Grobbelar et al “SARS-CoV-2 spike protein S1 induces fibrin(ogen) resistant to fibrinolysis: implications for microclot formation in COVID-19” Further comments about the research recommendations as there is nowhere else to put the comments: Additional recommendation for research is What are the most clinically effective interventions?' Important to include, as part of this, what treatment interventions are most effective on long covid patients. Are there treatments already used for other conditions that can help manage some of the symptoms? re.the last two research recommendations on effectiveness of exercise - it is better to use the term mobiility than exercise,or to use both, For many bed bound people, exercise is a long way off, just being able to be mobile and to complete simple daily self care tasks such as showering, getting dressed etc is more important and should be prioritised over exercise or combined e.g.

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				counting getting dressed as an activity. Interventions for these are needed long before exercise may be attempted for many. Also it should emphasise how to assess/triage for post exertional malaise before any form of even gentle exercise is considered. Any mention of exercise should also include acknowledgement of the need for careful pacing and self checking. It would be good to assess the effectiveness of pacing techniques and explore evidence on the importance of resting and pacing. Two questions ask if the effectiveness of (1) intervention and (2) exercise varies with different populations groups, but it could also be asked if it varies with different grouped symptoms, symptom severity, co-morbidities, etc. There are many patient safety risks with long covid.I think it is valid to assess what these are and ways to minimise the risks urgently e.g. what are the red flag symptoms and pathologies that may be being missed, how can testing for these be improved as well as urgent referral pathways mand interventions, what interventions may be harmful (e.g. due to heart conditions or exercise intolerance) or drug interactions, what are patients trying themselves that may be harmful and how can this be avoided (e.g. online, illegal, expensive, off licence medications drugs and supplements and their interactions with prescribed meds), is lack of sufficient emphasis on the need for recuperation rest and pacing leading to longer term health problems, to what extent are social and employment pressures exacerbating symptoms? what can we learn from patient experience of what is being tried,what is thought to be effective, what could be harmless or harmful or expensive and unnecessary? How are long waiting times to access and support affecting patient outcomes? Are multiservice team-led interventions resulting in better patient outcomes than e.g. GP only. A questions could be valid on different interventions for children, young people, pregnant women older people, disabled people, etc. This may be clinical intervention due to different symptom presentation but also differences in terms of accessing, understanding and applying interventions.

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University of Leicester	Guideline	CaseDefn		I find the case definition pragmatic and helpful. the term 'long-COVID' has become widespread and the acknowledgement of this and how this term fits with the case definition is clear.
Cardiff and Vale University Health Board	Guideline	CaseDefn		Interesting reading, nothing significantly new or nothing we have not seen. Scottish expert evidence is quite thought-provoking Comorbidities be seen across both physical and psychological medicine. Rehabilitation has to include vocational support. I was also hoping that the guide could add some clarity as to when or if a population post a time period actually becomes CF/ME? Is there a definitive presentation that makes post 6-12 months individuals Post COVID Syndrome, do we continue to say they are, or are they actually ME/CFS?
Royal College of General Practitioners	Guideline	CaseDefn		We believe the definition is the clearest and most appropriate currently available, however, dividing the long-term effects of COVID-19 into two separate diagnosis and giving them different names may be unhelpful for clinicians as evidenced by the use of the coding for “ongoing symptomatic COVID-19” which has not been widely used within primary care. (Clinical coding of COVID in English Primary Care BJGP August 2021). Whilst Patients prefer the term 'long-COVID', having just one time frame and one clinical definition (12 weeks Post COVID-19 syndrome) may be more useful for clinicians, improve coding and make it clear when the diagnosis is being made, especially in primary care. This, however, must not then be used as the time scale for referrals and investigation which should remain the same at 4 weeks and onwards. Other comments: Within the case definition, the explanation of the use of 'post' is very helpful and essential in highlighting that this case definition is only in reference to the period after the acute phase of infection, while recognising that the illness may still be ongoing.
Public Health England	Guideline	CaseDefn		From PHE our main comment on this guidance, as in the last round of consultation, remains that the proposed case definition still does not mandate any proof of infection (including antibody testing), and there is no sub classification within the very wide definition, hence interpretability and analysis is going to be incredibly difficult. This creates “noise” in

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				the system and anxiety for all those who self-identify with “long covid”. There are a number of different syndromes and until there is some sub-categorisation of these groups research into treatment and outcomes will be difficult to progress as will optimising management and long term support. P8 for the case definition of post COVID 19 syndrome: It would be helpful to acknowledge that people may have symptoms for reasons that are not post covid syndrome and not due to an “alternative diagnosis” as stated in the definition. People may feel unwell after a prolonged stay in hospital/ITU and it may be worth mentioning this specifically or changing the wording of the definition to incorporate this. e.g. “are not explained by an alternative diagnosis or pathology”. Furthermore, evidence suggesting some of the common symptoms listed could be due to the effect of lockdown/being in a pandemic but this is not mentioned anywhere in the guidance (this has been highlighted in studies which include controls). We remain concerned that the case definition still does not mandate any proof of infection including antibody testing, and there is no subclassification within the very wide definition, interpretability and analysis is going to be incredibly difficult.
Department of Health and Social Care (DHSC)	Guideline	CaseDefn		We recognise the rationale for not changing the definition that is provided. However, we believe that this will be disappointing for many, including patients, clinicians and researchers. From our perspective, a more granular definition would help improve the quality and comparability of research undertaken, as well as potentially enable an increased focus on available treatments. The existing definitions are broad and do not support distinguishing between those with severe symptoms and those who are less significantly impacted. This imprecision is not helpful to clinical service providers, nor in managing patient expectations. It is also unhelpful to policy-makers in shaping an effective cross-government/non-health response. Additionally, whilst we recognise the level of evidence required for guidelines is high, we were also wondering whether there is scope for the definition to be developed outside of the formal guideline process.

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UK Doctors Long Covid	Guideline	CaseDefn		We agree that no change is indicated, but please consider updating once WHO develop their definition of Post COVID-19 Condition, especially if there are significant variations between the two definitions. As WHO are referring to the condition as Post COVID-19 Condition, should it be considered whether this term should be adopted rather than Post COVID-19 Syndrome? This would enable the UK terminology to be consistent the WHO terminology, removing ambiguity. The WHO term allows for multiple subheadings to include organ pathology in different organ systems as well as the option for a specific Post COVID-19 fatigue condition. It removes the debate as to whether Post COVID-19 organ damage/sequelae fall within 'Long Covid' and whether Long Covid refers only to a Post COVID-19 fatigue condition.
Asthma UK and the British Lung Foundation	Guideline	CaseDefn		N/A
PACS19 Post Acute Covid Syndrome 19 support group	Guideline	CaseDefn		It would be useful to patients and their carers as many are not in patient support groups that: 1) Patients should be encouraged to join one of the many groups, particularly those that sit on these committees/stakeholders 2) That 'long covid' is included as a colloquialism (SIGN appear to not be using 'PCS' and 'long covid' in its leaflet which is adding to patient/GP confusion and in relation to snowmed codes still. Other collquial patient terms must also be included eg 'long haul', 'long tail', and variants of pcs/pacs syndrome or sequelae for patient clarity.
Long COVID Scotland Action Group	Guideline	CaseDefn		It is not clear whether you refer to the case definition within the guideline or the full document, as neither have line numbers, so we will refer to the case definition of page 8 of the guideline, including the supporting rationale Timeframes given continue to pose the risk of being not getting taken seriously if they don't meet arbitrary criteria. You continue to use the term 'post-COVID-19 syndrome' despite this term's inaccuracies and stigmas – it is highly biased and I'm concerned the panel continue not to listen to patients. There is

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				continual emerging evidence of viral persistence in some cases, making 'post' inaccurate, and both 'post' and 'syndrome' are terms used in other highly-stigmatised conditions, usually those which affect women, who already experience significant medical bias. This is not to say 'Long Covid' should necessarily be used instead, but more that 'post-COVID-19 syndrome does harm – it will continue to contribute to the misdiagnosis abuse of patients, particularly those who are vulnerable already; it is no less stigmatising than 'cripple'. This inaccuracy implies that Long Covid is merely a viral illness that clears up of its own accord. For some that may be so. For others it becomes a chronic illness.
#MEAction UK	Guideline	CaseDefn		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 remain based entirely on length of time since Covid-19 infection, with no evidence of a change in pathology at 12 weeks. Some people will have specific heart or lung problems whilst for others, post-exertional malaise (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. Why is the committee not recognising the prevalence of PEM post-Covid-19, and directing clinicians to consider coronavirus-triggered ME/CFS as a diagnosis? 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.
Long COVID Physio	Guideline	CaseDefn		Please share your comments here (referencing the specific page and line): Page 5, section 2.0 (Scope): "Clusters" should include the symptom post-exertional symptom exacerbation (also known as post-exertional malaise) within the list of symptoms, because there is enough evidence, standards and guidelines that reference the importance of this symptom especially in the provision of safe and effective rehabilitation interventions. For example: - Literature on common symptoms including post-exertional symptom exacerbation;

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				https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370(21)00299-6/fulltext https://www.medrxiv.org/content/10.1101/2021.06.11.21258564v1.full.pdf - Literature on aetiology and mechanisms of exercise intolerance; https://journal.chestnet.org/article/S0012-3692(21)03635-7/fulltext - CDC guidelines including post-exertional symptom exacerbation; https://www.cdc.gov/coronavirus/2019-ncov/hcp/clinical-care/post-covid-conditions.html - Rehabilitation briefing papers, standards and guidelines specifically referencing post-exertional symptom exacerbation; https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-2021_0.pdf https://www.albertahealthservices.ca/assets/info/ppih/if-ppih-covid-19-rehab-allied-health-practice-considerations-post-covid.pdf#page38 https://physiotherapy.ca/sites/default/files/site_images/Advocacy/long_covid_en-final-rev2.pdf https://www.csp.org.uk/system/files/publication_files/001745_Community%20Rehab%20Standards_A4_V7.pdf https://www.csp.org.uk/system/files/publication_files/001745_Hospital%20Standards_A4_V10_3.pdf https://apps.who.int/iris/bitstream/handle/10665/344472/WHO-EURO-2021-855-40590-59892-eng.pdf?sequence=1&isAllowed=y Clusters of symptoms should also include inappropriate tachycardia and orthostatic intolerance as associated with dysautonomia (eg: POTS) based on the prevenance in the expert testimony (Gp Capt Edward Nicol QHS), and exitsting literature: https://www.cdc.gov/coronavirus/2019-ncov/hcp/clinical-care/post-covid-conditions.html https://internal-journal.frontiersin.org/articles/10.3389/fneur.2021.624968/full https://link.springer.com/article/10.1007/s12026-021-09185-5?fbclid=IwAR054Og-JQV1WLtLUiM3tt1dGDzg41UhSy6yMd5ht_AQjXjm9eL6vKQoeq8 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7685310/ https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7976723/

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Faculty of Intensive Care Medicine	Guideline	CaseDefn		The definition of Post-COVID-19 syndrome is “signs and symptoms that develop during or following an infection consistent with COVID-19, continue for more than 12 weeks, and are not explained by an alternative diagnosis”. It is not clear whether an “alternative diagnosis” might include the so-called ‘post-intensive care syndrome (PICS)’. PICS does not have a strict definition (as far as I know), but encompasses the collection of symptoms (physical, psychological, emotional) that persist beyond hospitalisation for a critical illness. There is a large overlap between Common Symptoms of post-COVID-19 syndrome (section 12) and symptoms of PICS. Including PICS as an “alternative diagnosis” in the definition of ‘post-COVID-19 syndrome’, thereby excluding patients recovering after a critical illness from being diagnosed with ‘post-COVID-19 syndrome’, would be undesirable, as it could potentially exclude these patients from the measures described in this NICE guidance. The definition therefore requires clarification that PICS is not included as an “alternative diagnosis” excluding patients from the ‘post-COVID-19 syndrome’ definition.
Long Covid SOS	Guideline	CaseDefn		As stated previously, clarity for the purposes of clinical guidelines should not prevent research and data being collected into treatments and symptoms in the acute covid phase which may prevent or be an indicator of developing Long Covid.
Patient-Led Research Collaborative	Guideline	CaseDefn		The WHO's clinical case definition will include one definition, not two separate syndromes, for those who are ill for at least 8 weeks. Consider aligning.
The National Guideline Centre (ME/CFS guideline committee)	Guideline	CaseDefn		As mentioned above we note the potential for confusion with Post COVID-19 Syndrome and the diagnosis of ME/CFS as outlined in the diagnostic criteria in the draft ME/CFS guideline

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The National Guideline Centre (ME/CFS guideline committee)	Guideline	CaseDefn		As mentioned above we note the potential for confusion with Post COVID-19 Syndrome and the diagnosis of ME/CFS as outlined in the diagnostic criteria in the draft ME/CFS guideline.
SIGN Council Scottish Intercollegiate Guidelines Network	Guideline	CaseDefn		This document provides useful prevalence data and a structured view of management of this heterogeneous groups of symptoms / syndromes collectively known as long-covid. The differentiation of timescales to acute, ongoing or extended and chronic illness is a valuable distinction. The finding on page 9 that one study found a higher percentage of females after hospitalisation is perhaps not in line with local clinical data although we do concur with the higher prevalence of females.
Scottish Government	Guideline	CaseDefn		"The only comment on the NG188 COVID-19 rapid guideline is around the reference to our Implementation Support Note on Page 9. This immediately follows a section providing information on coding within SNOMED CT (the info system used in England). Within that context it would be helpful if the reference to the Implementation Support Note was more clear that this is also a source of information on the relevant codes for EMIS PCS and Vision (the info systems used in Scotland). As currently drafted it isn't clear that there is information on clinical coding within the ISN."
Long Covid Support	Guideline	CaseDefn		Whilst it is important to have specific clinical diagnostic criteria in order to facilitate access to support, provide the basis for planning services and to enable formal codes to be developed for clinical datasets (page 9, line 7 of rationale), it is important to acknowledge that to date there is insufficient evidence to assume that Long Covid is a continuation of an acute Covid-19 illness during the 'ongoing symptomatic stage' or that this stage stops at a definitive time (12 weeks). It is therefore important that professionals supporting patients at different stages of the illness eg 11 weeks vs 13 weeks are mindful that the patient may be experiencing the same symptom course at these two timepoints even though the diagnostic

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				codes and descriptors differ. We have major concerns about Long Covid (post-Covid-19 syndrome) becoming a diagnosis of exclusion (as also happened with ME/CFS). We would prefer it kept as an umbrella term to enable equitable access to services, and to then be considered alongside alternative diagnoses. This is because of the likelihood of co-morbidities and the need to identify and mitigate for these too. There is a risk that once one condition has been confirmed that all symptoms are put down to that and not adequately assessed. People who have had an acute covid infection may find their previous conditions exacerbated and may not return to their baseline function. New conditions may have also been triggered by covid-19. Recognition of covid-19 as the precipitating event needs to be logged and patients need thorough assessment and evaluation of all symptoms/resulting conditions. Concerned that by making Long Covid a diagnosis of exclusion that the impact of Covid infection on the public's health can be minimised. Identifying post-Covid-19 syndrome - needs to bring together our understanding of the multisystemic nature and appreciation of comorbidities because if everything is treated in isolation and post-covid-19 syndrome is seen as a diagnosis of exclusion then the effect on the child and adult population will be minimised and it is likely that people will have comorbidities missed. Giving anyone experiencing ongoing symptoms post infection a full screening and considering subsequent presentations to healthcare services within a set duration post infection as related, should always be explored.
Long Covid Wales	Guideline	CaseDefn		Long COVID, of course, is a new disease the course of which is, as yet, undefined precisely and so is a challenge to evidence-based medicine. The advice should be for practitioners to have an open mind and not exclude possibilities when considering a patient. They should consider the totality of a patient, their comments, their history, their symptoms and signs, and not concentrate on the minutiae of any one, and certainly not the results of any given test. Those of us medical practitioners who have Long COVID and so are highly informed, can very rapidly diagnose the condition in another individual, although we might struggle to say how we do so. We are probably picking up on patterns in symptoms and

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				what the individual says: "key phrases/words." This should be studied and incorporated in guidance so as to help colleagues who do not have such informed insight, and who may well be suffering themselves from unconscious bias.
British Thoracic Society	Guideline	CaseDefn		Agree not to change the case definition until new evidence provides a reason to change – good to see Long Covid included. Perhaps use the patient preferred spelling Long Covid unless your patient partners have specified a different preference.
Faculty of Pain Medicine of the Royal College of Anaesthetists	Guideline	EIA		Page 66 lines 147-152 The retention of existing and addition of new recommendations for support of underserved and vulnerable people are much commended. Still , further research in the prevalence of Post COVID syndrome in some of the groups is to be encouraged. Bearing in mind the impact NICE guidance has on healthcare provision it is an ethical mandate to provide further research on prevalence in specific underprovided and vulnerable groups, especially where evidence to date is insufficient.
National Institute of Health Research (NIHR)	Guideline	EIA		The fist impact assessment suggested that the higher rate of symptom reporting in women may be due to 'lower help seeking behaviours' from men. We know that most medical research is conducted with men but are increasingly aware that chromosomal sex differences impact disease pathways and treatments. NHS England collects self identified gender rather than biological sex, which will impede future research in this area.
Royal College of General Practitioners	Guideline	EIA		Page 63, line 31 – Can the committee consider expanding this section to include people who have had negative experiences of healthcare in the past? Some patients who already have pre-existing illnesses with overlapping symptoms to post-COVID-19 syndrome may be reluctant to seek out treatment for the long-term effects of COVID-19 due to poor experiences in the past. We believe it would be useful for healthcare providers to reach out to these patients and ensure a supportive relationship is in place should they seek out treatment.
Royal College of Speech and Language	Guideline	EIA		People with communication needs may miss out on care because they cannot advocate on their own behalf. They, also, may not have anyone who can advocate on their behalf. The RCSLT recommends that speech and language therapists are referenced in the core team.

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Therapists (RCSLT)				There is an inequality in access because of a mismatch of who should be in the core team between NICE and in national guidance.
UK Doctors Long Covid	Guideline	EIA		Where issues have been identified in the equality impact assessment please clarify how you propose to address these, for instance the negative experience of women accessing services, given that women are greater than 50% of the population being served?
Asthma UK and the British Lung Foundation	Guideline	EIA		Our only comment on the Equality Impact Assessment is to urge NICE to continue to consult with people with lived experience as part of this work.
Long COVID Scotland Action Group	Guideline	EIA		14.3 P67 219 It is good to see children included, however, this could be more embedded within the guideline. P68 242 and 259-264 Definitely agree with the point people of colour may be overlooked – this part should stay. There is significant data noting Long Covid and similar conditions impact women more than men, alongside a vast body of evidence that women have been failed by healthcare (medical bias) – yet the latter is not mentioned, instead there is postulation of 'males being overlooked'. This is significant unconscious bias and must be corrected; males and men do get Long Covid and this must of course be taken seriously, but you must consider the decades of research on women being abused and even dying in medical contexts due to being taken less seriously for their gender. P69 274 See the previous comments on gender – as the guideline currently stands, there are no attempts to mitigate the unconscious bias facing some people with protected characteristics, esp women, and people of all genders who have been gaslit by health professionals. This is not a slight against health professionals – many of whom are fantastic – but in the past year we've still seen thousands of people, usually women, experience abuse. In general, this section needs to go much further – various other vulnerable groups are left out and there is no guidance on how GPs use this information to really drive inclusion.

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Long Covid SOS	Guideline	EIA		p66 line 159 Sex: Hormonal reasons should be increased from ovulation to peri-menopause and early menopause due to the age range it is most commonly reported in women.
SIGN Council Scottish Intercollegiate Guidelines Network	Guideline	EIA		The equalities section is very well written and highlighted.
Long Covid Support	Guideline	EIA		61 (line 5) - The CDC Post-COVID conditions document for patients last updated Sept 16 2021 list 'changes in menstrual period cycle as a symptom'. This is something frequently mentioned by members of Long Covid Support both post infection and post vaccination Not including this in the NICE guideline risks women's concerns about this issue being dismissed and therefore risks their health. 61 Does effectiveness vary for different population groups (for example, sex, age, socioeconomic group, black, Asian and minority ethnic group communities or people with a learning disability)? You also need a 'why' component to this question and to consider systemic institutional factors such as racism and ableism. 63 - Although the focus is on adults, children and young people there is not a clear appreciation of the differences in presentation of these groups, nor the different social factors which may impact on these groups. Socio-economic and social factors definitely deserve more consideration. Older adults living in residential or nursing homes may not receive equitable assessment and intervention and this needs to be mitigated for. Young children and neuro-diverse adults who are not able to verbalise their experience should equally have access to healthcare assessment and review post infection, particularly where parents or caregivers are identifying ongoing concerns. The experience of trans and non-binary people particularly related to hormonal aspects which appear to be relevant in Long Covid needs careful consideration in service and screening tool design. Allowing self-report for those who are able to discuss aspects such as menstruation, pregnancy, sexual

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				dysfunction. 65 - Many self-management resources require a certain level of digital access, digital literacy, general literacy and health literacy. People should be supported with these and not left with resources that are inaccessible to them for these reasons. If someone can't get out of bed they won't be able to go to the library to access a webpage of information. As well as the impact of systemic racism, systemic ableism, homophobia, transphobia and fatphobia is endemic in health and social care. Consideration should be given to intersectionality and the appreciation of different layers of discrimination that people face. The added recommendation to "be aware of reduced performance or increased absence in work or education" is commendable, but needs to be widened as many people are not in work or education due to e.g. homeless, disabilities, care responsibilities, retirement. It should be about reduced ability to carry out any activities including work, education, caring, self-care, exercise, social activities as all affect mental and physical wellbeing. People may prioritise work and education at the expense of domestic tasks and self care for example.
Long Covid Wales	Guideline	EIA		It would be good to list "difficulty with words" / Specific Lexical Retrieval Difficulty as a symptom, which combined with brain fog / slowed mentation amounts to a disability in itself and thus worthy of attention under equality impact. Hence, conversation with and comprehension of healthcare practitioners and those around someone suffering will be impaired, as will the ability to use apps, let alone electronic devices, or gain benefit from leaflets. Speaking with a human being, preferably in person, is much to be preferred.
NHS England	Guideline	EIA		Page 64, lines 85-87: Those who have no fixed abode may be lost to follow up through the healthcare system. Page 65, lines 99-102 – could refer to this population as Inclusion Health Group

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				The link in the guideline in Section 2.3 takes the reader to the statement for v4.1 of the NICE VITT guideline.
Faculty of Pain Medicine of the Royal College of Anaesthetists	Guideline	General		The recommendation for the use of apps and online resources as part of a self management 'package' does contradict the earlier recognition of cognitive function impairment and 'brain fog' as causes for difficulty in using digital equipment. Specific recommendations on which (if any) apps should be used (as tested and safe) would be very helpful. We are very surprised of the lack of specific reference/recommendation to the need for pain assessment and management for a condition that lists pain (musculoskeletal, chest/cardiac, abdominal) as predominant symptoms. Still, this is a much needed guidance and we appreciate the 'live' approach taken in the view of ongoing developments and a hopefully broadening evidence base.
Welsh Government	Guideline	General		This is a welcome update. It recognises different approaches in different areas although some of the narrative perhaps does not always follow a more diverse approach . There is some repetition, and some parts if taken out of context may potentially be misconstrued which is partly my previous point, but it is difficult to mitigate against that fully.
Office for the Chief Allied Health Professions (AHP) Officer at NHS England and Improvement	Guideline	General		The office for the Chief Allied Health Professions Officer (England): 1. Note that on this document version reference has now been made to the role of speech and language therapists and dietitian in this pathway. Section 11, p57. The CAHPO office supports this update 2. Support the use of the WHO definition of functioning, disability, and health (page 6) 3. Acknowledges that technology is now a key method for all areas of delivery, including interacting with and supporting patients and delivering care and this needs to be part of the 'new normal'. We therefore agree in principal with the use of virtually hosted consultations as agreed by all parties. However, some groups may be disadvantaged by the rapid adoption of technological changes. Therefore, those delivering Long COVID services need to ensure any system changes are undertaken with due regard to the Equality Act (2010)

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Cardiff and Vale University Health Board	Guideline	General		Interesting reading, nothing significantly new or nothing we have not seen. Scottish expert evidence is quite thought-provoking Comorbidities be seen across both physical and psychological medicine. Rehabilitation has to include vocational support. I was also hoping that the guide could add some clarity as to when or if a population post a time period actually becomes CF/ME? Is there a definitive presentation that makes post 6-12 months individuals Post COVID Syndrome, do we continue to say they are, or are they actually ME/CFS?
Royal College of General Practitioners	Guideline	General		While we accept that COVID-19 is a new virus and more research on its effects is required before we know how to effectively treat it, there is a lot of established research on post-viral syndromes, including post influenza and SARS, which can provide evidence on the best methods of treatment. Can the committee confirm whether this evidence has been considered and if not, consider adding into the next update of the guidance? We were concerned that the names and confidential academic findings were provided in the evidence summaries of the "expert witnesses". This may be a breach of confidentiality, and in view of the controversial nature of this guidance, could also put those professionals at risk. Can the committee and NICE look at the risk with this data being provided to stakeholders (which also includes patient groups) and ensure the consent of those giving evidence was given to specifically share their name with all stakeholders as part of the consultation? If not, can NICE ensure that mitigations are put in place to protect the data and the identity of these individuals going forward? As a final general comment, we would like to add that navigating and responding to the guideline was not particularly straightforward for this consultation. The guideline was not numbered to match up with the response document provided, and the recommendations were not numbered either and therefore were not easily identifiable to respondents. While we recognise this is a living guideline and therefore needs to be flexible in its format, we would ask that for the next review, please could the guideline and response document be more clearly aligned and marked out to help the process of responding.

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Royal College of Speech and Language Therapists (RCSLT)	Guideline	General		The RCSLT recommends that an additional comment on the need for evidence on the effectiveness of interventions for voice disorders and interventions for swallowing difficulties (dysphagia) in post-COVID syndrome should be included. This is an area that warrants further investigation in research. Reference: Clave et al 2020. Oropharyngeal dysphagia in patients with COVID-19 https://clinicaltrials.gov/ct2/show/NCT04346212 The RCSLT understands that NICE/SIGN rely on ongoing evidence surveillance to review the evidence base, with which to make recommendations, and there is a need for rigour, as well as pragmaticism around this. The evidence reviews for this update clearly identified well-conducted systematic reviews and impressive, large cohort studies. We are pleased to see this commitment to robust evidence reviews to encourage evidence-based practice to provide the best possible care to people with post-COVID syndrome. NICE will be aware that the health care professions vary in size and research capability, and historically smaller professions have faced challenges in undertaking research. Being one of these smaller professions, speech and language therapy has done enormously well in terms of publishing research and collaborating with colleagues to do research on COVID-19 and Long COVID over the past 18 months. We commend and support the profession in these accomplishments. Where SLT-driven research has taken place, collaboration in this regard has happened, or other researchers who have a good understanding of speech, language, communication and swallowing needs have been involved in studies, we see quite high prevalence of these needs in long-COVID patients (e.g. Seeble et al, 2021 cohort study of 96 patients found that almost a third had 'problems finding words', 12 months after the onset of COVID symptoms). These studies may signal a key area of need for patients, who are best supported by speech and language therapists. To ensure that best patient outcomes are achieved and quality and equitable care are delivered, the RCSLT hopes that going forward, NICE will recognise the expertise in the profession through inviting a speech and language therapist to provide an expert testimony and consider some alternative, but still robust, evidence that highlights these areas. We have cited such evidence throughout our response, and summarise some key articles below. 1. Davis, H. E. et al. (2021)

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				Characterizing Long-COVID in an International Cohort: 7 Months of Symptoms and Their Impact. EClinicalMedicine. DOI: https://doi.org/10.1016/j.eclinm.2021.101019 Findings of note: All respondents to an online survey had COVID-19 related illness lasting over 28 days. The probability of participants symptoms lasting beyond 35 weeks was 91.8%. Over half of the participants in this study were not hospitalised (56.7%). • Approximately 35% of participants identified 'lump in throat/difficulty swallowing' as a symptom • Approximately 28% of participants identified 'changes in voice' as a persistent symptom • Almost 50% of respondents (See Fig 3) cited speech and language difficulties as symptoms, including 'difficulty finding the right words' (47%) and 'difficulty communicating verbally' (28%) • Around 85% of respondents reported 'brain fog' as a symptom, as well as 'poor attention' (75%) and 'difficulty thinking' (65%) • Temporal analysis of symptoms suggests three clusters of symptoms – cluster three includes speech and language issues, brain fog and memory issues and typically shows highest probability of this cluster of symptoms being in the second month onwards of infection. 2. Seeßle, J. et al (2021) Persistent symptoms in adult patients one year after COVID-19: a prospective cohort study. Clinical Infectious Diseases, ciab611, DOI: https://doi.org/10.1093/cid/ciab611 Findings of note: The majority of patients included were non-hospitalised (67.7%). Almost a third (32.3%) of patients in this prospective cohort study had 'problems finding words', 12 months after COVID-19 symptom onset. 3. Grahem et al. (2021) Persistent neurologic symptoms and cognitive dysfunction in non-hospitalized Covid-19 "long haulers". Annals of Clinical and Translational Neurology, 8 (5), 1073-1085. DOI: https://doi.org/10.1002/acn3.51350 Findings of note: Prospective study of 100 COVID-positive patients • 81% of patients reported brain fog 4. Halpin et al. (2020) Postdischarge symptoms and rehabilitation needs in survivors of COVID-19 infection: A cross-sectional evaluation. Journal of Medical Virology, 93 (2), 1013-1022. Findings of note: This cross-sectional study looked specifically at 100 COVID-19 patients who had been in hospital (either ICU or ward) but looked at the longer-term symptoms at both 4 and 8 week post-discharge. • Speech and swallow symptoms were reported by both ward and ICU cohorts including swallow problems, larynggeal sensitivity,

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				voice change, communication difficulty. • In this cohort, 20.6% of the ward patients met referral criteria for SLT (1 or more symptom reported) and 28.1% of the ICU patients met referral criteria for SLT – only 5.9% (ward) and 6.3% (ICU) were seen by SLT in hospital. • Fatigue was the most common symptom reported by 72% of those in the ICU group and 60.3% in the ward group. 5. Blomberg, B., Mohn, K.GI., Brokstad, K.A. et al. Long-COVID in a prospective cohort of home-isolated patients. Nat Med 27, 1607–1613 (2021). https://doi.org/10.1038/s41591-021-01433-3 This prospective cohort study (312 patients) did questionnaires with patients at 2 and 6 months after being ill with COVID (hospitalised and non-hospitalised aka 'home-isolated') Findings of note: • Severe fatigue at 6 months was present in 7% of home-isolated patients, and 24% of hospitalised patients • In 'home-isolated patients' the most common symptoms of mental fatigue were difficulties finding words (23%), difficulties concentrating (19%) and memory problems (18%) 6. Sudre, C. H. et al (2021) Attributes and predictors of Long-COVID: analysis of COVID cases and their symptoms collected by the Covid Symptoms Study App (pre-print https://www.medrxiv.org/content/10.1101/2020.10.19.20214494v1.full.pdf) Analysis of 4182 users' self-reported symptoms through the Zoe app. Findings of note: • Hoarse voice, sore throat, persistent cough reported (do not know how much, not the aim of the study, but fatigue predominated at 97.7%) • Hoarse voice in the first week of illness was predictive of long-COVID (OR=2.33 [1.88 - 2.90]) (along with 4 other key symptoms)
Public Health England	Guideline	General		The amount of resourcing required to do all the mandated assessments and referrals is considerable, and without a triaging of who to refer and when this should be escalated, I would be concerned that the current system could be easily overwhelmed. Again here having a differential criteria for review would be useful. Additional points: Given that poor general health (smoking, overweight, asthma) seems to be associated with long Covid, signposting to prevention services, such as smoking cessation/healthy weight services, would be useful. The guidance mentions referring to social prescribing, which is good – but this can be quite broad. It follows that if this were to be included in the guidance, that it

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				would be reflected in the booklet also. Pleased to see evidence for children and young people addressed, this is very helpful.
Department of Health and Social Care (DHSC)	Guideline	General		The following comments cover sections where this survey hasn't allowed for specific feedback. Section 7, Page 48 Current text: 'After the holistic assessment, discuss with the person (and their family or carers, if appropriate) the options available and what each involves. These should include...' DHSC comment: It might be useful to mention here that care can provided in the home as part of the patient's rehabilitation (not just at community hospitals). Section 9, Page 53: Current text: 'Agree with the person how often follow-up and monitoring are needed, which healthcare professionals should be involved and whether appointments should be carried out in person or remotely...' DHSC comment: Acknowledge the availability of specialist services such as mental health, olfactory (smell) training etc. Section 11, Page 57 Current text: 'Provide access to multidisciplinary services (these could be 'one-stop' clinics) for assessing physical and mental health symptoms and carrying out further tests and investigations...' DHSC comment: Is this referring to the long-covid clinics that have already been introduced? Would be useful to clarify if not. Section 16, Page 74 (definition of Rehabilitation. Preferred definition from DHSC's Rehab colleagues is below): Rehabilitation is an active and enabling process centred on people's needs designed to maximise mental and physical health, independence and occupation. In the context of ongoing COVID-19 symptoms, this may include providing information, education, supported self-management, peer support, personalised symptom management strategies and / or physical rehabilitation. (informed by WHO: Rehabilitation (who.int)) Reference - Wessex Strategic Clinical Networks : Rehabilitation is everyone's business: Principles and expectations for good adult rehabilitation Or Commissioning guidance for rehabilitation (england.nhs.uk) 2016, which also references the WHO definitions
Royal College of	Guideline	General		In future reviews of these guidelines it will be beneficial to gather expert testimony from NHS occupational therapists and other therapy colleagues involved in the assessment and rehabilitation of adults and children with post COVID-19 syndrome. There are a number of

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Occupational Therapists				local NHS teams who have been capturing quantitative and qualitative data and outcomes for a number of months, which will be valuable in further developing the guidelines. The expert testimony regarding rehabilitation that has been gathered for the current review is valuable, but the settings are not representative of NHS rehabilitation services, and do not capture the breadth of professionals involved. Although out of scope for the current consultation, there are a number of updates and improvements that could be made to other recommendations within the planning, management and rehabilitation sections of the guideline. We would welcome the opportunity to provide additional comments during the next review cycle. Our general comments are: • There is a lack of definition on what rehabilitation is and the role of Allied Health Professionals within this. • There is an excessive focus on diagnosis and very little on interventions addressing activities of daily living, functional ability and engagement in daily life. • There is little mention of quality of life, although this is a significant concern reported by people with lived experience. People want to be able to go about their daily lives and are unable to do so. • There is acknowledgement in the assessment section that functional impact is important, but there is minimal discussion of this within the sections on management and rehabilitation. • Best service delivery should be defined including rehabilitation and the roles within it – consideration of what therapies are effective. This may need to be based on local data and outcome measurement, whilst the evidence base is established. • There is little detail on health inequalities and the need for services to proactively address access to services and experience of services for diverse and underserved groups. • The recommendations around work require more detail – local evidence indicates a phased return is not adequate for most people, and is harmful in some cases. Personalised vocational rehabilitation should be provided by occupational therapists or other suitably qualified professionals.
UK Doctors Long Covid	Guideline	General		We have concerns regarding the evidence used and its applicability to the general Long Covid population: 1. Concerns about the evidence on children from an expert witness who has responded with limited answers to many of the questions 2. Concerns about the expert

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				testimony provided, particularly Nuffield (who excluded patients if too unwell to participate) and since Scotland have no Long Covid service, where does Locke's expert experience come from? 3. The stated premise of a 'desire to not over-medicalise Long Covid' by expert witness Locke is concerning as this is an unfounded opinion. The value of medical input, assessment, investigations and treatment should be evaluated by NICE. NICE guidance should not be based on an priori desire to shape the service in a specific way. 4. Why has the Delphi study (https://bjgp.org/content/early/2021/07/27/BJGP.2021.0265) not been included in the evidence assessment? This provides the current best practice options for management of different symptom clusters in Long Covid, why was this not utilised? Alternately why was the lead author, Brendan Delaney, not requested to give expert testimony? If you will accept expert testimony from Locke, why would you not accept expert testimony from him? 5. Research studies have been judged as low or very low quality yet they are being used to draw 'firm' conclusions on management, we appreciate the evidence is limited, but perhaps such 'firm' conclusions should not be drawn then. 6. Where is the Lived Experience expert testimony? 7. Why has there not been an evaluation of the current knowledge of underlying mechanisms? There are several mechanistic studies on endothelial dysfunction, abnormal shunting in lungs, abnormal oxygen use by tissues, abnormal brain MRI scans, abnormal immunological profiles, etc. This is in addition to the well recognised clinical syndromes that have an increased prevalence in the Long Covid population of diabetes, thryoiditis, myo-pericarditis, microvascular angina, spontaneous urticaria and mast cell activation, arthritis and connective tissue disorders etc. The guidelines are amiss in not drawing attention to the links and the increased prevalence of these conditions and the newly discovered underlying pathophysiology, as this would allow practitioners to better counsel and investigate their patients. The guidance needs to emphasise the importance of an initial face to face appointment involving thorough assessment and full examination with baseline bloods for known organ systems affected. Thereafter shared decision making can occur. Shared decision making assumes a knowledgeable patient and a supportive and understanding GP who understands the

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				condition well, this is not always the case and should not be an underlying assumption of the guidance. There is not much practical help or guidance for GPs other than a lot of speak of 'shared decision making'. This element is fine, but there also needs to be some practical guidance to facilitate at least initiation of investigation and management of patients' symptoms in primary care. There either needs to be a separate document guiding GPs to what some of the requested investigations/assessments are, or examples/explanations need to be placed within the text of the NICE guideline. Please provide guidance for GPs to better understand the condition as they are the primary gate keepers for patients: 1. Which screening questionnaire(s) should be used? 2. Which tool should be used in primary care to assess cognitive function that is quick enough to be utilised by GPs but sensitive enough to detect cognitive dysfunction in Long Covid? 3. Explanation of how to do a sit stand test 4. Explanation of how to do a 3 minute active stand test 5. Explanation of how to assess for POTS and the criteria for diagnosing this, including management options in primary care 6. Self management options – please provide examples of useful apps for dysfunctional breathing, learning to smell/taste again, as well as examples of support groups for the GP to tell the patient about. There needs to be clear reference to the NHSE Long Covid clinic structure guidance as too many Long Covid services do not have a clinician lead or full MDT through which to assess patients. Alongside this there should be a flow chart for optimal management of a patient through various services. Several flow charts would help with guiding primary care physicians through different pathways for the management of patients with different symptom clusters. There should be specific guidance on the possible use of pharmacological therapies for certain symptom profiles, this guidance is clearly laid out in the Delphi paper by Nurek at al (https://bjgp.org/content/early/2021/07/27/BJGP.2021.0265), which does not seem to have been included within the evidence considered. Overall there is a lack of sense of urgency in the document (people are losing livelihoods and homes) and lack of specificity in the guidance. There appears to be a move away from recommending basic investigations/assessments/management. There is a general 'watering down' of the

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				guidance and the implication that shared decision making and some rehabilitation is the solution for all patients with Long Covid and that there is no clear need for specific investigations/management. The guidance seems to ignore the significant amount of organ pathology in people with Long Covid, which gets missed if people are not investigated appropriately. This could have detrimental long term implications for patients if these conditions are not managed in a timely fashion. Long Covid is not only a fatigue like illness, there is significant pathology in many who are investigated appropriately and there are pharmaceutical options that can help to manage people's symptoms and improve the chances of success through rehabilitation programs. It is very confusing to us as a group of medical doctors affected in this manner that the national guideline body is choosing to turn a blind eye to this. Those taking the lead on this guidance need to reflect on whether the decisions they are making based on the limited evidence available, and the evidence that they have decided not to consider/include, are decisions based on what is in the best interests of the patients they treat. NICE should be independent, yet the decision not to 'over-medicalise' Long Covid has undertones of political rhetoric and concerns regarding NHS service provision.
Asthma UK and the British Lung Foundation	Guideline	General		We have a recommendation relating to section 7 on sharing information and continuity of care below: We feel that there should be a stronger recommendation within the guideline that suggests that HCPs provide rehabilitation plans for people leaving hospital. When asked in our August survey whether respondents received a written document to explain what was needed during their recovery (rehabilitation plan): Almost two-thirds (64.2%) of respondents said no they did not receive this information. Less than a fifth (18.5%) said yes, they did receive a plan. 13.6% said no – someone talked to me about it. 3.7% of respondents said that they could not remember. Once again, we think that any information that can help people with Long COVID-related breathlessness manage their symptoms through information and treatment, is welcome. We also have a further recommendation on research below: It may be helpful to review research into potential blood tests for Long

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				COVID. Researchers at Imperial College London have also been piloting whether Long COVID can be diagnosed through a blood test. Preliminary findings reveal autoantibodies in the blood of Long Covid patients that was not present in people who recovered quickly from the virus or had never tested positive for the disease. It is believed that instead of warding off infection, like regular antibodies, these autoantibodies were targeting tissues and organs. It would be useful for NICE to review this research: Long Covid blood test could soon be a reality, say Imperial researchers (medicaldevice-network.com)
Department of Health - Northern Ireland	Guideline	General		It is noted that an amazing amount of time and effort has gone into the evidence reviews and it is a great resource to prevent much reinvention of wheels. What is striking is how many of the publications on PCS are designated low or very low quality and hence most of the recommendations remain based on consensus. Overall it is very helpful that the guidance explicitly mentions the 'move away from doing lots of clinical tests' and instead advising clinicians to do bloods 'if clinically indicated'. This is reassuring as the CCG banner guidance agreed for GPs in N.I has taken this approach. It states that referrers might 'consider' some tests but none are obligatory. Also interesting in the paediatric evidence that there is even more explicit advice to avoid unnecessary investigation.
Fifth Sense	Guideline	General		I am providing a lay view on behalf of a patient support charity having not seen the booklet previously. The booklet is useful but would benefit from a more informative introduction explaining what are believed to be the underlying causes of Long Covid rather than just giving a long list of possible symptoms. This would help lay people to understand that long COVID encompasses a broad range of effects which can result from the initial COVID-19 infection, in a similar way to the longer term effects caused by other viruses. Perhaps one of your experts could produce a paragraph covering this along the lines of the following (which is probably factually incorrect, but is intended to convey the general idea): "We are not certain what causes the prolonged effects of COVID-19, but some possible causes of long COVID may include: • a reduced, or lack of, response from the immune system • injury to multiple organs, including the lungs, heart, and brain, which may take longer to recover

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				than the time it takes for the body to remove the virus. • relapse or reinfection of the virus • inflammation or a reaction from the immune system • deconditioning, which is a change in physical function due to bed rest or inactivity • post-traumatic stress These prolonged effects relate to the initial COVID-19 infection but are not necessarily linked to each other so they may be require separate treatment and may recover at different rates." I am replying on behalf of Fifth Sense, the charity set up to support people with smell and taste disorders. A significant number of our members suffer with Post Viral Olfactory Loss, resulting from a range of viral infections, including COVID-19 in recent times. A general comment from such members is that it would be useful for medical practitioners treating patients with PVOL to make them aware of Fifth Sense and I'm sure this applies equally to treatment of other symptoms benefiting from reference to corresponding support charities, many of which now carry COVID-19 specific advice on their websites. A list of symptoms with corresponding support websites would be a useful additional document which could be provided alongside this booklet.
Public Health Scotland	Guideline	General		The draft guidance and the review sheet, and the online form do not match easily, the numbers in this document "i.e. Section 9: Common symptoms" is actually just "12 Common Symptoms" in the draft guideline, and different again online – this makes it hard to pinpoint comments sections. Would be easier if aligned.
Science for ME	Guideline	General		Better focus on symptoms not attributable to identified tissue damage We think the guideline has improved by moving away from lumping all post-Covid symptoms into a Post-Covid-19 Syndrome, and instead suggesting that identified problems such as heart or lung damage be treated in accordance with standard clinical pathways. Inappropriate lack of reference to ME/CFS It is clear that a substantial proportion of people with 'Post-acute Sequelae of Covid-19' as it is now defined meet the diagnostic criteria of ME/CFS, or are likely to do so in time. See, for example Characterizing Long COVID in an International Cohort: 7 Months of Symptoms and Their Impact (https://www.medrxiv.org/content/10.1101/2020.12.24.20248802v3) where the most

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				common symptoms reported by people with Long Covid were fatigue (78%); post-exertional malaise - the defining feature of modern ME/CFS criteria (72%); and cognitive dysfunction (55%). There are numerous other papers from around the world reporting similar findings. Long Covid is a post-infection syndrome, just as the syndromes following SARS, MERS, EBV, Q-fever and Ross River Fever are. Provided post-exertional malaise is present and the symptoms are present for more than 4 months, these syndromes fall under the ME/CFS umbrella and will be best managed according to the soon-to-be published 2021 NICE ME/CFS Guideline. This extensive guideline, which has been prepared by NICE with a careful examination of the evidence over a period of some four years, sets out how people can be given safe care. We are pleased to see that the RCGP e-learning module for 'Post-Covid syndrome' is fairly good, and does refer to the post-infection syndromes following SARS-Cov1, MERS and the flu. It is therefore a shame, and inconsistent, that this guideline appears to completely ignore other post-infection syndromes and the resources available for them (for example, the 2021 NICE ME/CFS Guideline and ME/CFS patient charities) that could help support both people with Long Covid/PASC and the clinicians who care for them. The 'Managing the Long Term Effects of Covid-19' guideline should make the connection with ME/CFS (as the umbrella term for long-lasting post-infection syndromes involving post-exertional malaise) clear, and link to the 2021 NICE ME/CFS Guideline. Guidance on diagnosing ME/CFS, including diagnostic criteria, should be included in the guideline. Inappropriate focus on goal-setting The recommendations for goal-setting throughout the guideline look all too similar to the historic approach to treatment of 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-infection 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

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				the confusion between the 'objective' and the 'method' in terms of recovery. The objective is to be well enough to carry out normal activities. That in no way implies that the method applied 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. Need for better consultation process Now that there is a guideline in place, it is time to move to a better consultation process. The process should be public so that organisations are able to consult before making submissions. It should allow sufficient time for preparing submissions, bearing in mind that many of the interested organisations will be staffed by people affected by Long Covid and other post-infection syndromes. Without looking more broadly at the evidence, including that related to ME/CFS, and lessons learnt in other relevant guidelines such as the 2021 NICE guideline for ME/CFS, the guideline will increase the chances of money wasted on rehabilitative efforts that have no evidence to support them, and that have a real chance of causing harm. We hope that the committee will take guidance from those with a well-informed knowledge of ME/CFS, including the major national ME/CFS charities, in order to improve this guideline to better serve the significant number of people who have developed, and will develop a post-infection syndrome following Covid-19.

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Long COVID Scotland Action Group	Guideline	General		I'm deeply concerned about the ordering of information and the evidence used in this guideline, as well as some of the language used (not just the name of the condition). Some quality evidence has been labelled as biased, biased evidence has been considered, and knowns have been called unknowns – it is important for people on the panel and at SIGN/NICE/RCGP to have training in power imbalances and unconscious bias, including gender bias and medical bias – these are different from science biases but do overlap. The feedback we've had from GPs – who are already very busy with the pandemic – is that they don't find the guideline useful or usable, in part due to its length. Could a shorter, 2-3 page briefing document – fully co-produced with patients – be considered? Note: the implementation note created in Scotland had this purpose but sadly does not achieve this – it was strongly questioned by patients and other organisations and independent campaigners due to the risk of harm. A short document created from scratch could be beneficial. GET (graded exercise therapy) must be flagged as dangerous for people with symptoms of post-exertional malaise / post-exertion symptom exacerbation – there is ample evidence to support this and Long Covid Physio have excellent resources. In particular please include the following key messages for safe rehabilitation as outlined in the recentJune 2021 document, World Physiotherapy Response to Covid -19 Briefing Paper9.Safe Rehabilitation http://wprldphysio/sites/defauly/files/2021-06/Briefing-paper-9-Long-Covid-FINAL-2021.pdf The recent pause of the NICE guideline on ME is concerning; NICE, SIGN and RCGP must ensure for patient safety they champion the evidence for all chronic conditions. Again, this is another area where training in power imbalances and unconscious bias is essential. Patient expertise, including children, needs to be more embedded within this guideline in general. I'm not sure if patients are on the panel, but I'd recommend a patient and carer panel be set up for early input, and that means of inputting are made more accessible, and that people are paid for their time and expertise. While accessibility has improved, there are still literally hundreds of pages of copy and limited means to input, with no extensions offered – this is ableist, especially given people with Long Covid are very ill, and often juggling work and caring duties.

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#MEAction UK	Guideline	General		Overall we remain deeply concerned. This update was a chance for the committee to consider new evidence and their own emerging clinical understandings. However once again this issues around coronavirus-triggered ME/CFS are being completely ignored, presumably due to the stigma that has gripped ME/CFS for decades. There also remains a lack of mention of rest throughout the guideline, with a sole focus on rehabilitation and goal setting. While none of these strategies have a strong evidence base for efficacy, rest should not be ruled out. In all of life, rest plays an important role in enabling recovery. It should be explicitly mentioned in this guideline.
Long COVID Physio	Guideline	General		Page 7, Section 2.6 (Related NICE and SIGN guidance): The themes excluded in this guidance include post-intensive care syndrome, ME/CFS, and end-organ damage. However in the related NICE and SIGN guidance table (1) critical illness is sign-posted twice, but there is no sign-posting to ME/CFS (new draft guidelines) or end organ damage guidelines for common impairments in those living with Long COVID. This appears to be a disparity in focus for sign-posting. Page 38, Section 4 (Consensus recommendation) Learning from the context and language used in the field of HIV and AIDS, please consider the term key and vulnerable populations within the sentence "Support access to assessment and care for people with new or ongoing symptoms after acute COVID 19, particularly for those in underserved or vulnerable groups who may have difficulty accessing services" because not everybody is underserved or vulnerable but may be key. Suggested change to sentence to key, underserved or vulnerable groups. Page 39, Section 4 (Consensus Recommendation) Within the list of "Include in the comprehensive clinical history" it needs to also include: (A) sleep patterns/disturbance, and (B) triggers for episodes or fluctuations in symptoms. The rationale has included reference to fluctuating symptoms (therefore by proxy episodic disability), consequently it is critical to include within the comprehensive assessment triggers for changes in symptoms. The existing literature guides us towards this eg: https://gh.bmj.com/content/6/9/e007004 https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370(21)00299-6/fulltext

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				https://bmjopen.bmj.com/content/11/3/e047632 https://world.physio/sites/default/files/2021-06/Briefing-Paper-9-Long-Covid-FINAL.pdf https://www.medrxiv.org/content/10.1101/2021.06.11.21258564v1.full.pdf Page 42, Section 6 (Consensus Recommendation Rationale): The rationale identifies "They agreed that blood tests and exercise tolerance tests (if safe and appropriate for the person) would be useful for most people as investigations and baseline measures", however there is no identification or guidance on what safe and appropriate means. This has been explored at length in the following rehab publications, and it would be suggested to either sign-post to these existing resources, or cite the safety measures identified eg: excluding post-exertional symptom exacerbation, exertional; desaturation, orthostatic intolerance and cardiac impairment. https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-2021_0.pdf https://www.albertahealthservices.ca/assets/info/ppih/if-ppih-covid-19-rehab-allied-health-practice-considerations-post-covid.pdf#page38 https://physiotherapy.ca/sites/default/files/site_images/Advocacy/long_covid_en-final-rev2.pdf Page 45, Section 6 (Consensus Recommendation Exercise Tests) Include World Physiotherapy briefing paper within rationale as the appropriateness of the sit-stand test is directly discussed in the context of Long COVID and appropriate assessment with exertional or exercise tests. . https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-2021_0.pdf (page 12, safe rehabilitation statement 3, action). Page 46, Section 6 (Consensus Recommendation for people with postural symptoms) Include the following resources in rationale; https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-2021_0.pdf (page 13, safe rehabilitation statement 4, action) with reference to assessing postural symptoms with NASA lean test and active stand test. American Autonomic Association Statement https://pubmed.ncbi.nlm.nih.gov/33740207/ Page 49, Section 8.1 (consensus recommendation on self-management information and advice) This should include reference to the "Stop.Rest.Pace" message and the critical role of pacing as a self-management approach, indicated in the following:

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				https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-2021_0.pdf https://www.jospt.org/doi/10.2519/jospt.2021.0106 https://physiotherapy.ca/sites/default/files/site_images/Advocacy/long_covid_en-final-rev2.pdf https://apps.who.int/iris/bitstream/handle/10665/344472/WHO-EURO-2021-855-40590-59892-eng.pdf?sequence=1&isAllowed=y https://www.albertahealthservices.ca/assets/info/ppih/if-ppih-covid-19-rehab-allied-health-practice-considerations-post-covid.pdf#page38 https://world.physio/sites/default/files/2021-06/WPTD2021-InfoSheet3-Fatigue-and-PESE-Final-A4-v1.pdf https://world.physio/sites/default/files/2021-06/WPTD2021-InfoSheet4-Pacing-Final-A4-v1a.pdf https://world.physio/sites/default/files/2021-06/WPTD2021-InfoSheet2-RehabandLongCOVID-Final-A4-v1a.pdf Page 51, section 8.2 (consensus recommendation on rehabilitation) Modify the sentence “Include physical, psychological and psychiatric aspects of rehabilitation to guide management” with the inclusion of cognitive and social aspects. This sentence would be improved by saying “Include physical, cognitive, psychological, psychiatric, and social aspects of rehabilitation to guide management”. Page 58, Section 11 (Consensus Recommendation to Share Knowledge) Reconsider the example of 1-minute-sit-to-stand test as shared knowledge, as previously in the guidelines this was argued not to be required consistently. Instead it might be suggested to provide a different example eg: pacing or heart rate monitoring as self-management approaches, as recommended by World Physiotherapy. https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-2021_0.pdf https://world.physio/sites/default/files/2021-06/WPTD2021-InfoSheet2-RehabandLongCOVID-Final-A4-v1a.pdf https://world.physio/sites/default/files/2021-06/WPTD2021-InfoSheet4-Pacing-Final-A4-v1a.pdf Page 61, Section 13 (Recommendations for Research; Interventions) Include “Does energy conservation or pacing assist in improving symptoms of post COVID 19 syndrome?”. The current research question focus on exercise alone is inconsistent with current practice models in managing Long COVID symptoms. Case Definition Evidence Review: Page 7. Consider use of the

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				term “episodic” instead of changing symptoms, as conceptualised in this citation. https://gh.bmj.com/content/6/9/e007004 Signs Symptoms and Prevalence Evidence Review: Why was Davies et al not included, however this citation was included in the case definition? This seems like an important omission from the evidence for signs and symptoms. https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370(21)00299-6/fulltext
Faculty of Intensive Care Medicine	Guideline	General		9 Follow-up, monitoring and discharge No specific comments, seems reasonable. Note: there is overlap with NICE CG83 and NICE QS158 (Quality Statement 4: follow-up after critical care discharge) 10 Sharing information and continuity of care No specific comments, seems reasonable. Note: there is overlap with NICE CG83 and NICE QS158 (Quality Statement 4: follow-up after critical care discharge) 11 Service organisation No specific comments, seems reasonable. As above, the existing provision of critical care follow-up services, including for patients after COVID-19, is not specifically mentioned here. Note: there is overlap with NICE CG83 and NICE QS158 (Quality Statement 4: follow-up after critical care discharge) 12 Common symptoms No specific comments, seems reasonable. Note: the majority of ‘Common Symptoms’ reported after acute COVID-19 are experienced by patients recovering from critical illness, often called PICS. 13 Research questions A couple of suggestions: For patients who survived critical illness following COVID-19 infection, (how) does post-intensive care syndrome (PICS) differ from post-COVID-19 syndrome? How does PICS after COVID-19/post-COVID-19 syndrome differ from PICS following other similar conditions causing critical illness (e.g. community acquired pneumonia, influenza etc)? General comments This guidance includes hospitalised patients, but there is little mention of patients who are recovering after a critical illness related to COVID-19, and the evidence mostly does not include populations of patients who are recovering after intensive care. In fact, the document states that “themes excluded from the evidence search” include “management of other conditions with similar features to post-COVID-19 syndrome, for example Post Intensive Care Syndrome”. The

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				majority of 'Common Symptoms' reported after acute COVID-19 (section 12) are experienced by patients recovering from critical illness. The guideline acknowledges that NICE CG83 and NICE QS158 overlap with this guideline, and that NICE plans to assess overlap and determine if signposting or review of quality statements is needed. I imagine that the FICM LACI working group would welcome being included in this review if/as required.
Chest Heart & Stroke Scotland	Guideline	General		The evidence base for the revisions made include neither lived experience of Long Covid, nor the recent Delphi study https://bjgp.org/content/early/2021/07/27/BJGP.2021.0265 which provides the most up to date best practice for management of different symptom clusters. We have particular concerns about the comment made in Locke's expert statement about the 'desire to not over-medicalise' Long Covid, and the robustness of the expertise provided within that testimony when there are other more valid evidence sources such as the Delphi study, and at present very limited provision of Long Covid services in Scotland, which Locke represents. There appears to be a danger that the guidance is, over time, diluting the medical aspects of managing Long Covid (for example the pharmacological therapies which are highlighted in the Delphi study).
LongCovidKids	Guideline	General		Overall this is very comprehensive and has been well examined by reputable expert witnesses. As a representative of LongCovidKids, I am pleased to see the inclusion of PIMS-TC but would like to suggest some further exploration into the phenomenon of PANS neuro-inflammatory outcomes.
Long Covid SOS	Guideline	General		The length and complexity of documentation should be taken into account when setting consultations, so that stakeholders have adequate time to review. It should be recognised that advocacy and support groups are run by volunteers, often themselves with lived experience, who dedicate their time to ensure the lived experience voice is heard within the healthcare system.

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Patient-Led Research Collaborative	Guideline	General		Post-exertional malaise and menstrual symptoms must be included in list of common symptoms (evidence: https://doi.org/10.1016/j.eclinm.2021.101019). The lack of a comment on the new and updated recommendations does not indicate endorsement.
The National Guideline Centre (ME/CFS guideline committee)	Guideline	General		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 strongly propose that the harms reported by people with ME/CFS in response to some treatments should have been taken into account and led to a more conservative approach to the recommendations around rehabilitation, particularly for those people where fatigue and post exertional malaise is a major factor, and where the fatigue is not related to deconditioning secondary to a prolonged ICU stay, for example.
The National Guideline Centre (ME/CFS guideline committee)	Guideline	General		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 strongly propose that the harms reported by people with ME/CFS in response to some treatments should have been taken into account and led to a more conservative approach to the recommendations around rehabilitation, particularly for those people where fatigue and post exertional malaise is a major factor, and where the fatigue is not related to deconditioning secondary to a prolonged ICU stay, for example.
SIGN Council Scottish Intercollegiate Guidelines Network	Guideline	General		In terms of the recommendation regarding support for children, young people and adults who have reduced attendance, performance or attainment at school or work due to post covid 19 syndrome, whilst we agree that this is an important issue and it is helpful to have this problem highlighted, it is unclear as to who will provide this support and how we would assess the patient to understand this in more detail. While we recognise that these are local resource issues, we felt it important to highlight in terms of setting an expectation for patients that will perhaps be challenging for Boards to deliver at this time. On page 4 in the Recommendation box – how severe your COVID-19 what? Is the document referring to

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				symptoms or how unwell the individual was? This document and the MagicApp it refers to offers a simple and clear portal for clinically robust evidence as it emerges. The shared site for NICE, SIGN and RCGP information with the recommendation levels for intervention planning will support the evaluation and shaping of clinical services. The MDT focus of the document is useful given the recognised value of systematic and pragmatic symptom management and rehabilitation for this remitting, recurring and evolving condition after diagnosis by exception following clinical assessment and investigations. The guidance and App support the balance of medical co-ordination through primary care and the avoidance of over medicalising the condition.
Sheffield ME and Fibromyalgia Group (inc long COVID)	Guideline	General		The guidance is missing the crucial message to patients that rest, not activity, will reduce the risk of prolonging symptoms. Patients should be encourage to maximise their activity WITHIN their tolerance levels, not causing deteriorating symptoms, rather than by external factors eg goal-setting. The language of post-exertional malaise needs to feature much more in this guideline, and health care professionals, who largely do not understand these mechanisms, require additional training. This guideline would benefit from helping health care professionals understand the real experience of loving with post-COVID syndrome and the inappropriateness of the diagnosis of anxiety that patients are reporting and some academics are suggesting.
Scottish Government	Guideline	General		make sure ICU rehab and follow up programmes are recognised as a requirement
Royal College of Paediatrics and Child Health	Guideline	General		As this is a document which includes children, the reviewers suggest a review of the wording throughout to also include the person's parent or carer where relevant. The document should be more child and young person and carer focused.
Royal College of Psychiatrists	Guideline	General		The College largely welcomes the update to the guidance, but has made a couple of specific points on the new and updated recommendations. Other more general comments were: • Given our improved understanding and knowledge of the condition, it was

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				unexpected that the thresholds for referral to psychiatric care were not updated. The guidance could therefore have clearer criteria for psychiatric referral. • Although the symptoms of long-covid can range from mild, self-limiting symptoms which are noticeable but do not impair function or affect quality of life, there are some symptoms which can be severe. The guidance could increase its emphasis on showing that at the severe end of the spectrum, symptoms can be incapacitating and distressing, and the significant impact this can have. • The guidance makes it explicit that the syndrome is similar to CFS/ME which may helpfully reduce the risk of post-COVID-19 syndrome being regarded as a purely organic syndrome. However, this is included within the section of 'themes to be excluded from the evidence search'. This could be construed as mixed messaging.
Long Covid Support	Guideline	General		As a living guideline we anticipated being able to comment on each of the recommendations and to better understand why certain aspects were kept the same or deleted based on research and practice developments since the last update. The rationale as to why certain sections of the guideline have been deleted is unclear as these sections have been removed from the document 'COVID-19 rapid guideline: managing the long-term effects of COVID-19' that we are supposed to be reviewing, yet still feature in the table of points to review as referenced in this document. For example 5.8 [DELETED] Consider referral from 4 weeks for specialist advice for children…6.3 [DELETED] Tailor monitoring to people's symptoms and discuss any changes…6.4 [DELETED] Consider supporting self-monitoring at home, for example heart rate… Not all points as listed in the above table have been marked as either New or Updated in the document COVID-19 rapid guideline: managing the long-term effects of COVID-19 How has evidence been defined? Where did you find the evidence? What was the cut off date for including evidence? Key pieces of patient-led research such as Recommendations for the recognition, diagnosis, and management of long covid: A Delphi Study (Nurek et al 2021 British Journal of General Practice) and documents produced by Long Covid Physio and World Physio have seemingly not been considered. Evidence has been considered from the Australian

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				taskforce and the World Health Organisation via the Magic App. Have the CDC guidelines for post acute covid syndrome been considered? Or WHO Europe Support for rehabilitation: self-management after COVID-19-related illness by Sivan et al The definition of what constitutes evidence seems inconsistent, e.g. reference is made (p49, Rationale line 5) to "This was based on qualitative evidence of patient experience and expert testimony" yet widespread patient reports as well as published research on symptoms such as menstrual disturbance and post exertional symptom exacerbation are discounted. Where decisions to update were made by consensus recommendation, who was on the panel? How were the panel selected? What proportion of panel members had lived experience? Why were there no expert testimonies from patient advocacy groups and patient researchers? There seems not to even be a requirement that expert witnesses meaningfully involve patients in all aspects of the development of their service or research, or work in partnership with patients or patient groups. We know that some of the experts from whom you have taken testimony do not meaningfully involve people with Long Covid as equal partners in their work. The Expert Testimonial by the Defence Consultant Advisor in Medicine discussed patients accessing medical pathology and rehabilitation pathways concurrently. It would be helpful for this guidance to advise on appropriate screening that allows people awaiting pathological investigation to access support, care and rehabilitation in a timely manner, particularly around fatigue/energy management. Need to highlight where exercise tolerance testing is not appropriate, e.g. screening for PEM (De Pauls) - see Long Covid Physio. If offered should be a full cardiopulmonary exercise test (CPET)- this will identify the low VO2 max and the early achievement of anaerobic threshold characteristic of energy depleting conditions such as Long Covid and ME, where there is a clear issue with mitochondrial oxygen utilisation (see multiple papers from Workwell foundation and others). Does early exercise rehabilitation assist in improving symptoms of post?COVID?19 syndrome? This research question also needs to consider under what circumstances is it contraindicated? Studies exploring this question need careful design, consideration of how to report people that drop out, reporting of harms and long term follow

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				up to assess whether benefits or harms are short term or extended. As an example the Expert Testimonial by Nuffield Health group reports the drop out in the group is because people were returning to work/had other commitments. From our group members we know that they often dropped out when exercise moved to the gym or because of Post Exertional Symptom Exacerbation which is not mentioned in the exclusion criteria. People found the group sessions beneficial for peer support but often sat out of exercises. AHP Professional Advisor Testimonial notes a concern re historical lack of services for other conditions CFS/ME, chronic pain, fibromyalgia, LTC management. The existence of poor pathways of support for other chronic conditions should not impact on development of services based on need arising post-Covid-19. Pathways that support people with post-Covid-19 syndrome could instead be used for the other complex LTC and create specialist services in complex syndromes. “Desire to not over medicalise” is a disappointing reflection considering the very real medical needs that have been highlighted and difficulties of patients being able to access medical support. The desire not to over medicalise is a purely a clinician-driven concern, ‘ patients are more concerned that they don’t receive enough investigations and effective treatment. We are concerned that the desire not to over-medicalise reflects an underlying belief on the part of some clinicians that Long Cvoid is either psychogenic in origin or it is a non-serious self-limiting illness that will right itself if given long enough. Concerns about over-medicalising seem to have been adopted from other areas of medicine such as diabetes and hypertension where the condition is well understood and can be safely managed in a non-medical way. Such an approach is not appropriate for a new human disease caused by a novel virus. Until such times as Long Covid has been demonstrated to be benign and unsuitable for medical treatment, it should be treated as a medical condition. We are far from having the knowledge to make that judgement while we are not yet two years into the existence of the condition. Future AHP workforce planning needs to be considered to meet demand of the growing amount of people living with Long term and chronic conditions. The note re waiting times and return to work are important. Perhaps DWP, employers also need to support services to allow employees to access

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				timely support. Although a good conversation model of rehabilitation can be beneficial, this needs to happen alongside thorough medical review and assessment rather than avoid diagnosing co-morbidities that can be treated successfully and reduce disability burden. The intervention question - What are the most clinically effective interventions (including social prescribing and structured community support) for managing post?COVID?19 syndrome? - Is social prescribing really a clinical intervention? What about occupational therapy and physiotherapy? Direct comparison of cheaper non clinically based interventions versus specialist input from qualified health professionals. Cost-benefit analysis (cheaper up front cost may not turn out to be so in the long run). It is vital that patients lead and co-produce the research questions and guideline development - an example of true partnership is the CDC guidance. We also wish to comment on exclusions from the evidence search (2.5): - Acute Covid-19: consider issuing advice alongside positive test results or clinical diagnosis that rest and recuperation can lead to improved outcomes. - Management of other conditions with similar features to post-COVID-19 syndrome: Where these are new diagnoses the respective NICE guidance should be considered alongside this one to ensure holistic assessment of the post-Covid-19 presentation is considered. - Management of end-organ damage: There is evidence that organ damage and microembolisms are not being picked up in many patients who have not been thoroughly assessed or received appropriate clinical tests. 'Absence of evidence' is no justification for inaction. Clinicians need to have informed discussions with patients about trialling treatments that have been effective for others, for example antihistamines, measures to support with symptoms of PoTS, etc. Patients are suffering and becoming disabled, losing livelihoods, homes, relationships, and often suicidal. Patients cannot wait years for trials to report. Document is hard to navigate and would have benefited from contents list. It was helpful to have this word document provided. thanks. It would have been good if it included the ability to comment on sections that were not changed but that reviewers felt could be improved. It would be good if we could submit this, as we used the word document on line to compile our comments as suggested, but then it is laborious to

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				copy and paste sections to the online portal. This is an extra burden on ill patient groups. However we appreciate that the online portal is much improved since the previou review. We were unable to access the MAGICapp as we did not have a password, this inhibited our ability to review. we were unable to see the recommendation labels (green, red, yellow, orange) which are meant to indicate the degree to which the benefits of an intervention to patients outweigh the disadvantages. On page 6 under 'Key questions' it lists under the heading 'Lived experience'; What are the views and experiences of people, their families and carers about: signs and symptoms of post-COVID-19 syndrome? access to services? how their symptoms were assessed? management of symptoms and rehabilitation? the patient care pathway information and support provided? It is not clear how effectively these views have been collected.
Long Covid Wales	Guideline	General		In retrospect, for those of us still suffering more than 570 days after initial infection, the clinical course fluctuates and is highly variable to the point of individuality, which we note is mentioned a number of times. Symptoms, signs and systems affected vary with time. While the clinical course may, on average, be to improve with time, this variability and long term course should be taken account of, especially in advising about pacing. For all that is known, some symptoms and signs may be permanent, especially if due to e.g. permanent post-COVID organ damage or immune dysregulation, so the concept of discharge must be relative and not absolute. Patients should be able to access services they have been referred to and not go through a whole new cycle of re-referral with concomitant delays and anxiety. It is essential that services be medically-led and multidisciplinary. Our lived experience is universal, in that all of us who have finally managed to get to see a hospital Consultant have been diagnosed with serious actionable pathology, including cardiac, respiratory, metabolic, autoimmune and coagulation abnormalities, all revealed by investigations only able to be requested by a Consultant, not GP (at least in Wales). Notably, these conditions were not diagnosed in primary care and many did not present with symptoms or signs classically recognised, e.g. for cerebral venous thrombosis.

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				Hence, we would strongly recommend that cases should be referred to a dedicated medical Consultant-led post-COVID clinic with a very low threshold for referral. We note the recommendations regarding further research, but we are surprised at the lack of recommendations regarding pharmacological treatments, especially when such great advances were made with acute COVID-19. While the formal evidence base remains to be established, 'mass observation' amongst those of us who have been given various common medicines could be used to give some guidance. As they are very established medicines with a known and good safety profile, much is to be gained at low risk by working with patients to find medicines from which they may benefit, and such results could be gathered centrally to form an evidence base, as with acute COVID-19. These include: H2-blockers (e.g. famotidine), NSAIDs, beta-blockers, topical/intranasal steroids, inhalers etc. It does a considerable amount for a patient's morale to be given something that may help. It is accepted that by no means any given medicine will help, which goes for the whole of medicine, not just the after effects of SARS-CoV-2 infection, and we are all intelligent to realise that while there is yet to be some miracle cure for everything, certain medicines may provide significant benefit. Similarly, amongst us we have not noticed any definite effect of vaccination on our symptoms, although some of us have experienced moderate/severe systemic and local reactions due to prior immunity from natural infection, and it is noted in this regard that some countries, e.g. Switzerland, grant immunity certificates to those who have had natural infection plus one dose of vaccine – they don't expect them to endure what are, in effect, two unnecessary boosters. Rehabilitation is, naturally, mentioned a great deal. Our experience is that this disease comes from within and that while there is a place for rehabilitation for physical effects due to post-COVID damage or admission to intensive care, the best advice is to tell patients that when their disease has run its course they will be able to return to an active life, but while it is still active they should not try and e.g. exercise their way out. Regarding mental health, we have all found that being seen by an experienced medical practitioner in secondary care is immensely helpful. The relief at being seen and taken seriously, examined and cared for by being investigated, diagnosed

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				and treated is very significant and has alleviated anxiety and depression, which, of course, in turn has meant and would mean a significant reduction in pressure on primary care and psychology and psychiatric services. The very human benefit of the 'laying on of hands', an established medical principle thousands of years old, seems to have been forgotten. There is an over-developed concern in the guidance at "over medicalisation" which is not warranted and we fear stems from unconscious bias (perhaps itself stemming from previous bias regarding Chronic Fatigue Syndrome and Myalgic Encephalitis). As patients affected with a new condition which may and does have serious consequences in terms of actionable pathology we want to be medicalised. We welcome it, we do not fear it and the medical profession need not either. We do not wish to be kept at arm's length by non-medical (or medical) practitioners, who with the best will in the world, do not have the diagnostic expertise and do not have the rights of prescription or access to the tests required. The very act of seeing a medical practitioner with sufficient expertise and seniority does a huge amount to improve one's mental health, thus alleviating in one go the great anxiety with being delayed, gas-lamped and not heard, as well as the anxiety with suffering from undiagnosed conditions which now can be treated. Lacking from the list of neurological symptoms is being "lost for words". Those of us fortunate to be seen by a Specialist in Clinical Linguistics have been diagnosed with Specific Lexical Retrieval Difficulty, as seen after e.g. encephalopathy. This has been most reassuring given our fears that we were developing dementia. We have not lost memory and thus words, rather we struggle to find the right or best one, and in reciprocation find it hard to follow conversations (especially online in e.g. Zoom or Teams calls) or read. Combined with the reduced and slower mentation of "brain fog" this amounts to a disability in itself, and so all should be alerted to being aware that speaking quickly, expecting interaction with an electronic device or even email or text message, may be very difficult or even impossible. This is an important aspect of access in this illness which, if not recognised, adds to the totality of anxiety.

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British Dietetic Association	Guideline	General		We feel that this guideline should highlight nutritional screening and assessment as an essential part of patient care. Given the well-documented links between COVID-19 and nutrition, all health professionals should be advised to consider dietary changes as part of any holistic management and rehabilitation plan. We note an update to the symptoms list and suggest nutrition plays a significant role in the management of many of these, with a huge number of symptoms affecting eating behaviours, energy requirements and nutritional status. In addition, obesity and overweight are consistently mentioned as risk factors in the literature, but no validated tools have been recommended to screen for these. Therefore, we suggest more specific guidance is made available to clinicians to support the nutritional needs of people with covid-19, to ensure the identification of dietary issues and the effective management of these. Dietitians need to be highlighted as an essential part of the multi-disciplinary team to signpost clinicians and to advise all people with significant burden in primary care settings. This will improve patient care and has the potential to reduce healthcare costs (see Hickson, M., Child, J. and Collinson, A., 2018. Future Dietitian 2025: informing the development of a workforce strategy for dietetics. Journal of human nutrition and dietetics, 31(1), pp.23-32.). We understand the rationale for excluding the paper by Gobbi et al., but suggest the following are considered: (1) Cawood AL, Walters ER, Smith TR, Sipaul RH, Stratton RJ. A Review of Nutrition Support Guidelines for Individuals with or Recovering from COVID-19 in the Community. Nutrients. 2020 Oct 22;12(11):3230. (2) Louca P, Murray B, Klaser K, Graham MS, Mazidi M, Leeming ER, et al. Modest effects of dietary supplements during the COVID-19 pandemic: insights from 445 850 users of the COVID-19 Symptom Study app. BMJ Nutr Prev Health [Internet]. 2021 Mar [cited 2021 May 25]; Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8061565/ (3) Calder PC. Nutrition, immunity and COVID-19. BMJ Nutrition, Prevention & Health [Internet]. 2020 Jun 1 [cited 2020 Aug 31];3(1). Available from: https://nutrition.bmj.com/content/3/1/74

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NHSEI - Specialised commissioning	Guideline	General		We are pleased to see much of the Personalised Care agenda covered in this document. This exercise has been unnecessarily time consuming and tiresomely onerous due to opaque presentation using MAGICApp and shamefully poor preparation of the consultation exercise with no regard of the stakeholder's experience. For example, the recommendation numbers above do not tally to the section numbers in the guideline e.g. Recs 1.1 to 1.10 above are not numbered as such and occur in section 3 without numbering, other than the recommendation "[NEW] In addition to clinical symptoms..." which randomly occurs in section 4. Having been involved in developing 20 NICE clinical guidelines and having commented on probably 20 more, I have never seen such a badly executed exercise. Even with a trained eye, it is very difficult to read the information provided across different documents and different sections and then check this back against the information presented in the guideline document, and then relate this to the rationales for the recommendations given, especially as some information is inaccurate or missing. Other points: Table p11 Outcome: Symptom duration Mean duration of symptoms was 7.2 months - no evidence presented for 1 of the 3 studies

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				Table p15 The footnotes 1-12 for this table indicate that the all results come from Ref 4 Domingo 21. The reference list immediately below includes Refs 4, 5, 7, 8 9 and 10, but results for these studies are not represented in the Table. Have these all been omitted in error or is the reference list incorrect? Eg Why are the fatigue results for the Michelen 2021 SR not reported in this table? Table starting on page 18, only including the information "Difference: fewer" under the absolute effect estimates column seems at odds with, for example, the conclusion of female sex being significantly associated with increased risk of having symptoms lasting 4 weeks or more since acute COVID-19 illness. Please provide an explanation for "Difference: fewer" or remove. In the same table, the contributing references would seem to be Refs 8 and 11, so why are refs 6 and 7 included in this list – have results for these been omitted in error or is the reference list incorrect? Certainty of the evidence p22 - ….serious imprecision (due to only 1 study contributing to an outcome or the confidence interval crossing the line of no effect). To which evidence table does this point refer? Having only one study contributing to an outcome's result is not a reason to downgrade for imprecision in the GRADE handbook. MAGICApp incorrectly includes this as a default setting, but yet as far as I can see there are no footnotes making this point in a corresponding evidence profile nor indeed could I find the corresponding evidence profile.

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The Royal College of Pathologists	Guideline	General		RCPath members did not submit any comments to the below consultation
The Royal College of Nursing	Guideline			We do not have any comments to add on this guideline. Thank you for the opportunity to contribute.