Management of the long-term effects of COVID-19

Targeted peer consultation on draft scope
Comments table

23/10/2020-27/10/2020

ID	Stakeholder	Document	Page no.	Line no.	Comments
1.	All Wales Therapeutics & Toxicology Centre	Scope	'1'	'General'	The case definition is not precise enough and need refining. Specifically, confirmation of recent COVID-19 infection by PCR or antibody assay should be part of the definition in order to exclude non-COVID cases. Should also differentiate severe COVID (hospitalisation with either evidence of pneumonitis and/or systemic inflammatory response syndrome).
2.	All Wales Therapeutics & Toxicology Centre	Scope	'1'	'23'	Definition of acute case need to be precise: recommend 28 days from first day of onset of symptoms.
3.	All Wales Therapeutics & Toxicology Centre	Scope	'3'	'3'	"Young people": again, imprecise terminology. Clear definition required.
4.	All Wales Therapeutics & Toxicology Centre	Scope	'5'	'7'	Are pre-existing ME/CFS patients excluded or those with de novo feature? This could be reconsidered since those at greatest risk may be those with pre-existing ME/CFS. In addition, there is considerable overlap with fibromyalgia. If it is decided to exclude ME/CFS then fibromyalgia should also be excluded.
5.	British Infection Association (BIA)	Scope	'Page 2 and general'	'Line 12 and general'	Without a clearer definition of COVID there is a risk patients will be at risk of alternative diagnoses being missed and receiving inappropriate treatment. Basing the diagnosis of COVID purely on a clinical syndrome and relegating objective diagnostic testing to a purely supportive role "with or without a positive SARS-CoV-2 test" misses the opportunity to target services to patients who will benefit most from them. COVID illnesses with mild / non-specific acute symptoms may still trigger long-term sequalae. Alternatively, applying a stricter more characteristic clinical definition will miss cases. It is important therefore that microbiological /immunological confirmation that COVID infection has occurred should be part of the definition of Long COVID.

ID	Stakeholder	Document	Page no.	Line no.	Comments
					Serological testing already performs well and is rapidly improving. The degree of certainty could be stratified. Eg. Microbiologically confirmed COVID – positive acute PCR test (or other) or positive serology at an appropriate time point after the acute illness Clinically probable COVID – based on a characteristic clinical syndrome including possibly radiological testing Clinically possible COVID - any compatible syndrome (e.g. viral respiratory tract infection) without a positive COVID test.
6.	British Infection Association (BIA)	Scope	'Page2 '	'2'	Post COVID syndrome “continue for more than 12 weeks”. This seems inconsistent with lower down where 3-4 weeks from the start is specified
7.	British Infection Association (BIA)	Scope	'Page 3'	'12'	“symptoms consistent with COVID-19 that continue for more than 3 to 4 weeks from the start”
8.	British Society for Allergy and Clinical Immunology (BSACI)	Scope	'2'	'26'	The list should include “immunological” as well, given the lymphopenia during the acute illness and unknown complications/effects of this post-COVID (for example on T cells and risk of subsequent viral infections).
9.	British Society of Rehabilitation Medicine	Scope	'2'	'9,10 & 11'	Some patients experience blurring of the boundaries between the acute phase of COVID-19 & longer term consequences. For those who have an acute hospital admission the transition from acute to longer term consequences may be easier to define, but that may not be the case for people who self manage in the community & who may not present to primary care services
10.	British Society of	Scope	'2'	'18 to 22'	Agreed that this is a reasonable approach & aligns with recommended respiratory follow-up for people who have been treated in hospital and have positive radiology. For those who have had a long period of

Management of the long-term effects of COVID-19

Targeted peer consultation on draft scope comments table

23/10/2020-27/10/2020

ID	Stakeholder	Document	Page no.	Line no.	Comments
	Rehabilitation Medicine				treatment on critical care this may need to be longer, especially if they have sustained neurological consequences (neuromyopathy, brain injury); for those people it will be difficult to disentangle symptoms attributable to post COVID-19 from those due to their neurological condition, so the time may need to be extended for those individuals to say 6 months
11.	British Society of Rehabilitation Medicine	Scope	'4'	'9'	Presumably the risk factors that will be explored will include pre-COVID-19 physical & mental health problems, such as- people who have medically unexplainable symptoms or physical presentations which may be psychologically mediated pre-existing chronic fatigue syndrome pain syndromes (eg:fibromyalgia)
12.	British Society of Rehabilitation Medicine	Scope	'4'	'14 - 16'	Can impact on relationships & caring responsibilities be included? Impact on ability to participate in education should be included
13.	British Society of Rehabilitation Medicine	Scope	'4'	'17, 18'	Before embarking on investigations a comprehensive history of evolution of symptoms & restriction on abilities, including pre-COVID abilities & medical/mental health issues, should be taken. Physical examination is essential, because some patients may have undiagnosed neurological or musculo-skeletal diagnoses.This will then guide interpretation of post-COVID-19 difficulties, & so guide investigative pathways
14.	British Society of Rehabilitation Medicine	Scope	'4'	'19'	It is important that referral to specialist care includes specialist Rehabilitation Medicine services which have the involvement of a Consultant in Rehabilitation Medicine within the multi-disciplinary team. Rehabilitation Medicine specialists have the expertise to disentangle multiple symptoms & so aid in the diagnosis of causation & impact on individuals
15.	British Society of Rehabilitation Medicine	Scope	'5'	'9 -11'	There is likely to be overlap between post-COVID-19 syndrome & post-ICU syndrome (which is not clear cut). How will overlapping symptoms & experiences be attributed to one or the other? Patients in Wave 1 who were treated on critical care tended to be discharged from hospital without evaluation of potential neurological or physical consequences, so post-ICU syndrome was not explored or diagnosed in those patients. This is likely to be the case in Wave 2 also with pressure on acute beds
16.	British Thoracic Society	General	''	''	The definitions are sensible and are in concordance with anecdotal clinical experience. Post COVID syndrome is just that, a syndrome; usually with a complexity of physical and psychological

ID	Stakeholder	Document	Page no.	Line no.	Comments
					issues. Current 'best practice' consists of screening before referral into a multidisciplinary (one stop) assessment clinic which affords identification of the full range of problems with plans to address them. The scope as set out could result in a failure to explore this model. Individual symptoms could lead to a number of disparate referrals to secondary care specialist services. This 'screen - MDT assessment' model should be explored within the scope.
17.	British Thoracic Society	General	"	"	Care is required with terminology elsewhere in the document. There needs to be clarity between Covid follow up (which will include many but not all people with post-Covid syndrome) and management of post-Covid syndrome (which will occur in only a proportion of people offered Covid follow up and some not). We agree with the scope detailed here, that the structure and organisation of these services should be included, but they shouldn't be considered the same thing.
18.	British Thoracic Society		'2'	'12'	As noted above the initial case definition is critical. The document suggests (page 2, line 12) "The person was diagnosed with COVID-19 based on clinical symptoms, with or without a positive SARS-CoV-2 test (PCR, antigen or antibody). This clinical diagnosis can be made retrospectively based on symptoms alone for those who self managed their acute illness." This definition risks including people never proven to have COVID who have lockdown-induced psychological morbidity or non-specific post-viral fatigue. The case definition should be tightened to people proven PCR positive or, if PCR negative, very high clinical suspicion of Covid , i.e. bilateral pneumonia on CXR or typical lung changes on CT scanning.
19.	Chartered Society of Physiotherapy	Scope	'1'	'18-21'	Suggest clarification that people with Long Covid may or may not have been admitted to hospital, may or may not have been admitted to intensive care and may or may not have organ damage
20.	Chartered Society of Physiotherapy	Scope	'2'	'2'	Suggest "Symptoms that develop or worsen following an infection" rather than "new symptoms"
21.	Chartered Society of	Scope	'2'	'6-7'	Possible re-wording: "Regardless of timescale the possibility of Long Covid or an alternative underlying disease should be regularly considered and assessed in a timely way"

ID	Stakeholder	Document	Page no.	Line no.	Comments
	Physiotherapy				
22.	Chartered Society of Physiotherapy	Scope	'2'	'9'	Concerns about use of “post-Covid-19 syndrome”. “Post”- it may not be clear when or if the acute phase has resolved. Signs and symptoms may not be apparent in the acute phase but develop in later stages, not might not be continuous. “Post” implies that the symptoms from the Covid infection are no longer there and have a different origin. NIHR Living with Covid Themed Review states that recovery trajectories are not linear, often is a cyclic disease, moving around different systems and fluctuating in severity, with periods of relapse.
23.	Chartered Society of Physiotherapy	Scope	'2'	'16-17'	Concerns about use of “post-Covid-19 syndrome”. “Syndrome”- NIHR Living with Covid themed review suggests there could be three syndromes (Post-Intensive Care Syndrome (PICS), Post-Viral Syndrome and Long-Term Covid Syndrome) under the umbrella term of Long Covid. People may experience more than one syndrome at the same time therefore it is difficult to distinguish post-Covid-19 syndrome as an isolated syndrome. Also, potentially there is a sub-group of patients whose symptoms may be related to pre-existing long term conditions, or may be exacerbated by Covid-19.
24.	Chartered Society of Physiotherapy	Scope	'2'	'23-28'	Suggest revision: “Clusters are distinct patterns of signs and symptoms which may arise from any system in the body, often overlap and change over time”
25.	Chartered Society of Physiotherapy	Scope	'1-2'	'Page 1: 22-26 Page 2: 1-7'	Until more is understood about long term effects of Covid-19, suggest definitions are just based on duration of symptoms i.e. short duration instead of Acute Covid-19 infection (3-4 weeks), medium duration instead of Ongoing symptomatic Covid-19 (4-12 weeks) and long duration instead of Post-Covid-19 Syndrome (over 12 weeks). Use of the words “acute”, “infection” and “syndrome” may be misleading. When more is understood about different emerging clusters and recovery trajectories this could be further defined.
26.	Chartered Society of Physiotherapy	Scope	'2 and 5'	'Page 2: 29 Page 5: 6-13'	Suggest that exclusions should relate to patient groups/case definitions rather than themes to be excluded and therefore page 5, lines 7-13 are moved to page 2, line 29.
27.	Chartered	Scope	'5'	'7-9'	Change “management of” to “people with”

ID	Stakeholder	Document	Page no.	Line no.	Comments
	Society of Physiotherapy				
28.	Chartered Society of Physiotherapy	Scope	'5'	'9-11'	It may not be possible to distinguish PICS/ME/CFS from Long Covid as signs and symptoms may be related.
29.	Chartered Society of Physiotherapy	Scope	'5'	'12-13'	Suggested re-wording: “People presenting with predominant/isolated signs and symptoms that can be more appropriately managed with an existing condition/care pathway e.g. end-organ damage, end of life, oncology, pre-existing comorbidity”
30.	Chartered Society of Physiotherapy	Scope	'3'	'10-13'	Suggested additions: Researchers and policy makers to be added to first bullet point (lines 10-11) “employers; independent, third sector and voluntary providers of social support” as a separate bullet point below line 12 Suggest “independent” as well as private healthcare services (line 13)
31.	Chartered Society of Physiotherapy	Scope	'4'	'1-6'	Suggest “investigation and assessment” are reordered to “Assessment and investigations” as assessment would usually occur first (line 2). Suggest changing “Referral”- to “integrated models of care and coordinated referrals pathways” (line 3).
32.	Chartered Society of Physiotherapy	Scope	'4'	'8-18'	Suggest inserting another key question: “what assessments should be carried out to identify individual need and determine appropriate management and rehabilitation requirements?” (above line 17)
33.	Chartered Society of Physiotherapy	Scope	'4'	'19-21'	Suggest replacing the question under this heading with three key questions: “What models of care & rehabilitation are required to integrate and coordinate the management of the diverse signs and symptoms of Long Covid, taking into account specialist care and rehabilitation and different settings?” “How do assessments and investigations inform integrated models of care and coordinated referral pathways?”

Management of the long-term effects of COVID-19

Targeted peer consultation on draft scope comments table

23/10/2020-27/10/2020

ID	Stakeholder	Document	Page no.	Line no.	Comments
					“How are services accessed in a timely way and in response to individual need?”
34.	Chartered Society of Physiotherapy	Scope	'4'	'22-30'	Suggest replacing first question as follows: “What management approaches, rehabilitation interventions, pharmacological and advice and support improve the physical, psychological, cognitive and social problems affecting usual activities, including work and leisure?” (lines 23-25) Suggest replacing the second question as follows: “What monitoring is helpful to assess deterioration, fluctuation or recovery, and the ongoing appropriateness of the referral pathway?” (lines 26-28) Suggest adding in two additional key questions: “What is the role of families, carers and support groups in management and rehabilitation?” “What validated outcome measures are available and appropriate for people with individual needs?”
35.	Chartered Society of Physiotherapy	Scope	'4-5'	'Page 4: 31-32 Page 5: 1-4'	Suggest adding an additional bullet point: “the needs of families and carers”
36.	Chartered Society of Physiotherapy	Scope	'General'	'General'	Suggest an additional section: “Recommended/priority areas for further research”
37.	Chartered Society of Physiotherapy	EIA	'Age section'	''	Suggest removing “living alone” as an older person may live with other people who also have difficulties accessing care (2nd paragraph). Additional point: some existing services have age referral/exclusion criteria which may lead to inequitable access.
38.	Chartered Society of Physiotherapy	EIA	'Disability section'	''	Suggest including an additional point about the frequently reported symptoms of Covid that may result in disability and create challenges for seeking help and accessing services.
39.	Chartered Society of	EIA	'Sex section'	''	Emerging evidence suggests there is a higher incidence of Long Covid for women (https://www.medrxiv.org/content/10.1101/2020.10.19.20214494v1)

ID	Stakeholder	Document	Page no.	Line no.	Comments
	Physiotherapy				
40.	Chartered Society of Physiotherapy	EIA	'Other definable characteristics section'	''	Suggest an additional point about people living in care homes due to: high incidence of Covid-19 infection in care homes, prevalence of Long Covid currently unknown restrictions in accessing care homes (infection control) existing services have exclusion criteria which may lead to inequitable access.
41.	Chartered Society of Physiotherapy	EIA	'Other definable characteristics section or new section'	''	Suggest an additional point about people with pre-existing co-morbidities, including mental illness/mental health, which may create challenges for seeking help and accessing services.
42.	Chronic Long Covid Support Group	Scope	1'	22-23'	We identify 'acute covid 19 infection at weeks 1-2 . Phase 1 . A set of initial 'symptoms' are typical & clinically some remain throughout the later 'ongoing' phase eg, ice pick headaches, diarrhoea, loss of smell & taste, lung pressure, chest tightness etc Many of these 'continue' throughout 'ongoing' phase and the post covid syndrome phase, what we refer to as a kind of 'baseline' effects.
43.	Chronic Long Covid Support Group	Scope	1'	24-25'	We feel that Phase 2 is 'ongoing symptomatic covid' and is typical at around week 3 onwards and our records/documents indicate it lasts around 7-8 weeks so weeks 3 - 10.
44.	Chronic Long Covid Support Group	Scope	2'	1-2'	Phase 3 the 'post covid syndrome' phase -we saw this by week 10. We feel that week 12 is too late to recognise this phase. We catalogued the changes, a shift away from the initial 'symptoms' of viral infection and a gradual phasing in of new 'effects' as opposed to 'symptoms'. We feel this would recognise the change into a post viral illness(es). We feel it is important to recognise that one phase does not end and another one starts. There is continuity throughout phase 1 & 2. Phase 3 sees the phasing out of the initial symptoms and changes to 'effects'. We recorded and documented the illness right from the beginning including cataloguing, getting patients to personally graph their journey and completed a table of effects at week 10 onwards. We also created a photobank and started documenting it in detail with timelines. We were the only support group to have documented it for the

ID	Stakeholder	Document	Page no.	Line no.	Comments
					purposes of Government Ministers, NHS England and medical/research teams. We also catalogued every effect being reported by at least 25 patients (to ensure that other illnesses did not get included).So our weeks are based on solid evidence.
45.	Chronic Long Covid Support Group	Scope	2'	2'	'New symptoms' might be replaced with 'there is a notable shift from symptoms to effects' including new ones not previously seen We feel examples would be supportive here eg, by week 10 we recorded on our survey (which was the first one to be done on ongoing covid patients and remains open) extensive cases of psychological disturbances like flashing lights, strange noises, hissing sounds at night, vision changes, cognitive changes, hair loss, keratin structures growing from the scalp, mastitis, rashes, bruising, Whilst there may be 'clusters; it is more a case of some common baseline effects eg, joint pain starts being reported, back pain, shoulder blade pain, chronic fatigue, nausea, gastric bubbling, food intolerances, incontinence in both men & women. menstrual cycle involvement, testicular swelling & yeast infections, followed by both random and 'on and off 'effects like nerve vibrations in the muscles, seizures, shivering, adjustment to temperature changes eg, covid toes, cramps in muscles, breast lactation in women in their mid 40s to 50s.
46.	Chronic Long Covid Support Group	Scope	2'	2;	We feel it should be noted that by around weeks 20 onwards (approximately) that some of these effects phase out, but that there are cyclical aspects eg, the 5th month relapse and many effects wax and wane with some repetition of initial post covid syndrome effects. Many report a noticeable 'relapse event of 2-3 days up to 2 weeks of feeling feverish, fatigued, prominent malaise with other random things thrown in.
47.	Chronic Long Covid Support Group	Scope	2	8-11'	We have photos and documents to support these statements. we documented 180 effects on patients during the 'post covid syndrome phase'. On average most of us had between 50 to 85 effects, with most having 35 a week even in week 25. We feel this needs to be recognised in the scope since many medics think we have a few symptoms or one. References 'acute cases being resolved'. However, this is not the case and gives the impression that people are recovered or that one thing stops then another starts. We feel that the word 'acute' in phase 1 might be a little misleading to patients/doctors as it implies the serious part is over, when in fact, phase 3 probably has the most debilitating 'effects'. Perhaps a rewording of phase 1 might be worthwhile? eg, 'acute illness has usually ended' might be replaced with 'the initial phase 1 of infection & its symptoms have been replaced with effects. ie a gradual phasing rather than stoppage.
48.	Chronic Long	Scope	2	6-7'	'possibility of an alternative underlying disease is also being assessed'. Most patients have not been

ID	Stakeholder	Document	Page no.	Line no.	Comments
	Covid Support Group				assessed at all, or told over the phone they have anxiety. What other illnesses are being looked at? We feel its important to state them. We have seen secondary illnesses develop as a consequence but not other illnesses developing alongside post covid syndrome. Perhaps s it would be better to reword this as ‘other illnesses can be ruled out during this time. However, we have reservations about this since given that this physiological illness is so complex in its effects (multi system, probably blood vessel, mast cell, t- cell related, multi organ involvement and now showing organ damage eg, mitral valve prolapses) it is going to be futile to ask clinicians/GPs to rule out other illnesses. It is obvious and a major source of frustration for patients that GPs have been told to rule out other illnesses to match the criterion for the Your Recovery app. How long, given that the NHS looks at one issue at a time eg, referral to neurology? when in fact what is needed are post covid syndrome clinics which will look at a multitude of system effects. To ask GPs to rule out other illnesses is really impossible and many report feeling unable to do this.
49.	Chronic Long Covid Support Group	Scope	2	8'	Should be more defined. ‘ Signs and symptoms that continue after the acute phase of COVID-19 illness 10 has resolved.’ This needs rewording to be clearer. For example, ‘a notable shift from the phase 1 infection & it’s symptoms to a phasing in of effects including existing and new effects that can wax and wane and are more serious. Our patients feel the post covid phase is the worst whereas here it comes across that infection period is the most acute. We feel this is a little misleading. the effects are long term with most of us at 7 to 8 months. Overall reading the scope the initial infection reads to be more critical, when in fact, phase 3 post covid syndrome with its complexities and serious effects we have logged, are in fact, quite serious and acute.
50.	Chronic Long Covid Support Group	Scope	2	11'	the acute illness has usually ended’. This is an inaccurate statement. Again there is a feeling that there is labelling that the infectious phase is the most serious and people are over it. In fact, the r´al acute illness has only just started. This could be reworded with ‘the initial infectious phase has resolved or largely resolved. (You could also reference that the contagious phase is over).There is no reference to being contagious and this would help patients families, many of whom are scared their family members are still contagious (many have been banished to bedrooms for months on end). We feel that line 11 should also reference that whilst the infectious period has largely resolved, another set of effects are now in operation.
51.	Chronic Long	Scope	3	12'	We feel that GPs etc need our catalogue of effects, to refer to, since many patients have struggled to get

Management of the long-term effects of COVID-19

Targeted peer consultation on draft scope comments table

23/10/2020-27/10/2020

ID	Stakeholder	Document	Page no.	Line no.	Comments
	Covid Support Group				taken seriously by GPs and other GPs who have read up are not sure what are clinical symptoms (effects). NICE has our catalogue. It contains almost 200 effects. This is necessary to ensure that if GPs are asked to rule out other illnesses they can see what cumulative effects a patient is having. You have written those who self manage their 'acute illness'. Acute here is misleading since it refers to the initial infection phase 1. The word 'phase' might be better since it implies the gradual phasing in and out of symptoms and effects. Most patients have managed all 3 phases by themselves not only the initial infection so this needs replacing with 'those who managed any or all three phases of the illness.
52.	Chronic Long Covid Support Group	Scope	2	16'	'syndrome'. It is misleading to write that patients even with 1 symptom; We do not have patients exhibiting one or even a few effects, Most are having tens of effects. There seems to be a misrepresentation in the medical community that somehow we only a few effects, but in reality most of us are having twenty or more at the same time.
53.	Chronic Long Covid Support Group	Scope	2	18'	Discharge'. There seems to be an idea that with the Your Covid Recovery append here that after 12 weeks we will somehow we 'recovered' and 'discharged'. NICE needs to recognise the severity of this global public health disaster. Almost everyone in our group are still very sick with new effects ongoing and are now at 7 or 8 months. We do not understand how 'discharge' can even be contemplated when we have seen virtually no recovery in patients. We need scans and diagnostic tests, not as assumption that recovery is on the horizon since this is a new virus. 'Appropriate investigations' would be more meaningful. A sympathetic nod to the fact that for most of us, at least, recovery is not happening. Scans are showing very real organ damage and effects are ongoing and show no sign of improving in most patients. It leads to false hope. A plan to help us needs to be included. We sent a 10, 400 signature petition asking for post covid clinics to be set up in all UK major hospitals in July to NHS England and Matt Hancock. Can clinics be referenced in the scope?
54.	Chronic Long Covid Support Group	Scope	2'	28'	'Associated psychological impacts'. It is critical here to note the difference between mental health impacts brought about by the failure of the NHS to support patients. GPs have been dismissive, tests refused, antibody tests were promised and removed, families ignorant and so there may have been some impacts on people's mental health which will require intervention. However, CBT and GET which have been recognised in the medical community by more than 100 academics, MPs and experts on global public health as being based on failed research and called for to be removed has persisted with reference to ME/CFS patients. WE have already seen heart attacks in patients prescribed this therapy. You will find that there is already much resistance to GET/CBT in the post covid syndrome community.

ID	Stakeholder	Document	Page no.	Line no.	Comments
					Many of us are also showing ME/CFS effects and we think you need to be clear about what sort of psychological intervention is being proposed. We do not support this dangerous therapy and NICE stated in July that this would not be pursued but we see a heavy reference to 'psychological' support in this document later on. Perhaps we will get somewhere if we recognise that patients are urgently needing scans to determine if they have myocarditis etc since it is dangerous to be left untreated, there doesn't seem to be much reference to a treatment plan included?
55.	Chronic Long Covid Support Group	Scope	4'	16'	Equality Considerations Patients with organ damage and ME/CFS have been excluded. it says it is explained but we cannot see any explanation. We find it extremely strange that you would not include patients with organ damage or ME/CFS because many patients are exhibiting this. We find this discriminatory and very odd given you claim its a new virus and don't know anything about it, yet already decide to exclude certain groups. Disabilities also seems to be missing.
56.	Chronic Long Covid Support Group	Scope	key question	9	Key Questions Why are you only including 3 to 12 weeks? This aligns with the Your Covid Recovery app. We are already at 7 months or more??? so what happens to the patients beyond 12 weeks? The timeframe is unrealistic and leaves us puzzled. Who is advising you on the patients? We would be happy to share our documents and wide ranging data. Most of us then will not get included or be able to be supported-you are excluding most patients in a cope seeking to address the majorty of patients?
57.	Chronic Long Covid Support Group	Scope	key question	23	The remainder of the document is very 'psychological' treatment-heavy. We fear that CBT/GET is going to be proposed instead of treating us with a physiological illness. In fact, numerous groups issued a statement early last week that we were 'tdeeply troubled' to read on twitter by a NIce Committee member (aren't members and reviewers supposed to be bound by confidentiality?). Likewise, concerned to read publications of intentions to treat us with CBT/GET/Likewise, most patients have not been able to access services as consultations have been cancelled uk wide (we have documented it) yet other causes for the illness have not been ruled out. We are deeply concerned by the direction of this scope. We have already seen on twitter and elsewhere that there is plan to treat us with psychological treatment. This is not evidence based research as it was deemed to be a failure at global level. In fact it is used in USA teaching as an example of 'failed research'. Why then when it has been deemed dangerous and patients already prescribed it are having heart attacks is this terrible therapy being proposed? NICE also said in July they wouldnt follow it. What has changed? Patients are

ID	Stakeholder	Document	Page no.	Line no.	Comments
					going to FURTHER feel unsupported when they see ‘psychological’ everywhere since they have already been met by this beig diagnosed with ‘anxiety or patronisingly, ‘hysteria’. It is disappointing to read it in the public domain prior to this scope being issued, released by a committee panellist who is supposed to keep it confidential, and broadcasting and publishing papers on how they propose to manage us with CBT/GET, How about we invest new money in post viral illness research which can be based on ongoing covid patients? The idea that post covid syndrome is different from ME/CFS is misguided. Dr Anthony Fauci, Director of the United States’ National Institute of Allergy and Infectious Disease Institute thinks Long Covid is beginning to look very much like ME/CFS, as does Professor Anthony Komaroff of the Harvard University Medical School. Professor Komaroff has much experience in the field of ME/CFS and has published widely on the subject. Moreover, private clinics established here in the UK are showing almost a mirroring of effects eg, mitral valve prolapse. Many of our patients have been diagnosed with ME/CFS. Long Covid often manifests with the following: Persistent fatigue, sometimes variable, never relieved by sleep and progression to severe insomnia, Post exertional malaise, frequently delayed, frequently crippling, Severe muscle pains, often worsened by exercise, Cognitive difficulties, Alcohol intolerance, Dysautonomia and changes in blood pressure Long Covid appears different only insofar as it has presented in pandemic numbers, unlike ME/CFS which is sporadic and endemic. The list above would apply equally to both, and attempts to separate the two are quite artificial. We have many patients with both. By stipulating this viewpoint it deprives the patients of years of research, especially the more recent, from which they could benefit. To deny both ME/CFS and organ damaged patients to be included in this scope, we feel, is a major let down and does not make sense. It risks ‘gaslighting’ ongoing/post covid patients and replicating the damage done to thousands of ME/CFS patients. To have waited 7 or 8 months to get the clinics several key post covid patient support groups have tirelessly foughty for, to read of these exclusions and following the same pattern of dismissing ME/CFS which we know is manifesting in thousands already is a major flaw of the scope. It will be subject to ridicule both by professionals and patients. We hope you will reconsider this exclusion and it will afford great opportunities to develop major research in long covid and post viral illnesses. Since NICE are currently addressing the dangers of GET/CBT in the treatment of CFS/ME in the review of ME/CFS guidelines, it would make sense to include it, as a parallel illness, instead of treating them separately. We feel very strongly about this and also excluding those with organ damage-this is because Perspectum (Coverscan) that many of us took part in are already seeing 40% of patients with at least one organ damaged and 25% with two or more. Myocarditis and mitral valve prolapse being major effects which are

ID	Stakeholder	Document	Page no.	Line no.	Comments
					also indicative of ME/CFS.
58.	County Durham CCG	Scope	'General'	'General'	Please include recommendations on implementation and resources with the backdrop of current (and on-going) major pressures on the NHS. Considerations include: patient and regulatory expectations; NHS staffing; equipment.
59.	County Durham CCG	Scope	'P1-2'	'p1/24- p2/28'	Please provide guidance on the role of antibody testing in the diagnosis and management of ‘ongoing symptomatic COVID’ and ‘post-COVID-19 syndrome’
60.	County Durham CCG	Scope	'p2'	'1-28'	The case definition will be over-inclusive if only one symptom is necessary, if the symptoms are a ‘catch-all’, and if biochemical/biological confirmation of previous infection does not form part of the assessment. There is significant cross- over with other post-viral (and bacterial) syndromes.
61.	County Durham CCG	Scope	'3 (and relates to 2)'	'1-5 (12-15)'	This section covers persistent symptoms but potentially not those who develop Long COVID after having had few symptoms and/or no antigen test?
62.	County Durham CCG	Scope and EIA	'3 EIA p4'	'14-19 EIA 1.3'	Please consider the issue of equality for non-COVID patients struggling with normal daily physical and mental functioning after illness/ surgery (+/- Intensive Care Unit stays) who might currently lack access to resources, or whose services may be redirected in response to this guideline.
63.	County Durham CCG	Scope	'4'	'10-18'	Our regional centre (Newcastle) assesses patients with Long Covid through a multi disciplinary clinic and has developed a screening questionnaire, and is collecting data on complications and outcomes. You may wish to contact them when collecting evidence?
64.	CRG Complex Rehabilitation and Disability	Scope	'2'	'1'	The term Post Covid 19 Syndrome is a better fit with NHSE Framework for Long Term Conditions than the term Long Covid. The 12 weeks would allow for the normal recovery from a complex illness.
65.	CRG Complex Rehabilitation and Disability	Scope	'2'	'13'	A comparison of rates and duration of Post Covid 19 syndrome between those with a formal diagnosis through PCR/antigen/antibody and those diagnosed purely on symptoms would be really useful data.
66.	CRG Complex Rehabilitation and Disability	Scope	'2'	'18'	12 weeks would fit well with the post critical FU of 12-24 weeks.
67.	CRG Complex Rehabilitation and Disability	Scope	'4'	'27'	A needs assessment would be beneficial at this stage to determine rehabilitation requirements. The determination of validated outcome measures to be collated to determine whether or not interventions are effective, or to determine groups that where there are/are not effective.
68.	CRG Complex Rehabilitation	Scope	'5'	'9'	Excluding some of these conditions will be very difficult as the symptomatology of Post Covid 19 syndrome has significant overlap with many other conditions including (but not exclusively) CFS, ME,

ID	Stakeholder	Document	Page no.	Line no.	Comments
	and Disability				IBS, anxiety, depression, PTSD, Fibromyalgia. Some may be exacerbated by Covid 19.
69.	CRG Complex Rehabilitation and Disability	Scope	'6'	'1'	Can the NICE guidelines for pulmonary rehabilitation be included? The are aimed primarily at COPD and asthma but do have an evidence base. Can the NICE guidelines for FM be added? They are useful in what is unlikely to work but also covers many of the symptoms.
70.	CRG Complex Rehabilitation and Disability	Scope	'3'	'13'	Private providers should be included. If wave 2 should have a similar impact on NHS services as wave 1 the private providers will need to be involved in the assessment and treatment of Post Covid patients.
71.	Individual (and member of Doctors Long COVID Support Group)	Scope	'2'	'2'	Key thing is to ensure that has had appropriate investigations at this point, Wording in this line?to include "symptoms which last more than 3 months or develop after 3 months.
72.	Individual (and member of Doctors Long COVID Support Group)	Scope	'2'	'9-11'	Really important statement
73.	Individual (and member of Doctors Long COVID Support Group)	Scope	'Theme link'	''	Not yet operational (I presume)
74.	Individual (and member of Doctors Long COVID	Scope	'3'	'18-19'	We actually do not know whether there is a preponderance of females over males. THis is often stated but seems to be based on Time Spector's data, which only looks at those who self-report. There is probably significant bias in this reporting as many people with prolonged symptoms stop reporting whilst their symptoms are ongoing. In particular, many people who are test negative no longer report-since it is

ID	Stakeholder	Document	Page no.	Line no.	Comments
	Support Group)				explicitly stated that only those with positive test results are being analysed. IN addition, It is more likely that women join groups, access healthcare and report using apps. We simply do not know the rates in men and women as the biases are lkely so strong.
75.	Individual (and member of Doctors Long COVID Support Group)	EIA	'2'	'Age'	Where is the evidence for higher rates of reporting of prolonged Covid problems in older groups? If you look at the demographics of the long Covid support groups, and studies which number thousands, the average age is 42-again and ranges from people in their 20's to a few in their 60's. We are talking a problem of people in working age groups! I really feel this statement is inaccurate-would like to see what evidence it is based on. The same proviso about the 80% of cases being in women as I have made in point 4 above. N.B. article written by Prof C Chew—Graham and Ashish Chaudary on men's health-seeking behaviour and Covid.
76.	Individual (and member of Doctors Long COVID Support Group)	EIA	'2'	'Age'	Reporting by those in older groups is highly likely to be affected by lack of access to electronic communication as well i.e. 'apps' and computerised studies.
77.	Individual (and member of Doctors Long COVID Support Group)	EIA	'3'	'Belief'	I notice that views and beliefs in society are polarised at the moment by a number of things. I notice that people who are considered 'lockdown deniers' or 'anti-mask' are criticised frequently, and it may be that this affects how they are perceived when they access help, or may prevent them seeking help. I realise that 'belief' in this sense may relate to Religion but could not find another relevant place to make this comment.
78.	Individual (and member of Doctors Long COVID Support Group)	EIA	'3'	'Socio-economic'	I believe there are many potential socio-economic factors which may disadvantage, including the mentioned difficulty in accessing care. However, in addition, many people will lack access to computers, and in particular, we should consider literacy issues. This is common and will prevent people from being able to use 'apps', take part in research, get through systems to make a GP appointment/access hospital clinics. THis must be very much exacerbated by consultations and appointments moving on line. Plus all the on-line patient portals which are difficult to set up and which require literacy skills and access to computers.

ID	Stakeholder	Document	Page no.	Line no.	Comments
					If they find it more difficult to access healthcare services, they are unlikely to get the specialist referrals and tests that many people will need. I am concerned that the cost of buying over the counter treatments to help symptoms is very much affected by poverty and lack of access to information.
79.	Individual – Dr Ramzi Khamis	Scope	'1'	''	Duration- In my expericne cardiovascular symptoms can be up to 6 months. 12 weeks is too short certainly for the VASIS type 3 like symptoms. Therefore these guidelines should go beyond the current few papers describing the syndrome up to 12 weeks. We are seeing many patients with well documents cardiovascular pathophysiological abnormalities much longere than this and guidance will be required to tackle these patients' problems. Some patients don't even present till week 16-20 as they wait for the symptoms to disappear.
80.	Individual – Dr Ramzi Khamis	Scope	'1'	''	Duration- In my expericne cardiovascular symptoms can be up to 6 months. 12 weeks is too short certainly for the VASIS type 3 like symptoms. Therefore these guidelines should go beyond the current few papers describing the syndrome up to 12 weeks. We are seeing many patients with well documents cardiovascular pathophysiological abnormalities much longere than this and guidance will be required to tackle these patients' problems. Some patients don't even present till week 16-20 as they wait for the symptoms to disappear.
81.	Individual – Dr Ramzi Khamis		''	''	Also very important to note that a lot of the Long covid issues are cardiovascular and therefore adequate resources need to be dedicated to the cardiovascular aspect of the guidelines.
82.	Long Covid Scotland	Scope	'general'	'general'	The lack of a guideline has not helped patients access healthcare for this new set of ongoing symptoms that appears to vary with each patient. Introducing a guideline is therefore welcome, but given the limited knowledge, every effort must be made to ensure the scope is sufficiently broad to encompass all patients suffering from prolonged symptoms following suspected Covid19 infection.
83.	Long Covid Scotland		'2'	'1'	Patient groups have worked hard to achieve recognition of the term Long Covid and have embraced the term as sufficiently broad to encompass all with varying symptoms. It would therefore feel significant to continue using this term when developing guidelines and treatment options to avoid confusion and respect the contribution of patients' lived experience when capturing what is known into formal information.
84.	Long Covid		'3'	'10'	The inclusion of patients irrespective of availability of testing is welcome. To further ensure inclusivity,

ID	Stakeholder	Document	Page no.	Line no.	Comments
	Scotland				and counter potential bias, can you ensure the guideline is clearly communicated to all primary healthcare practitioners, including occupational healthcare, with relevant training if required? There is evidence more women than men experience ongoing symptoms but are more likely to be dismissed as having anxiety, depression or being menopausal.
85.	Long Covid Scotland		'4'	'9'	Risk factors. There are indications that more women than men may experience prolonged symptoms. We need sex disaggregated data to explore this. Evidence also exists that more women than men took on caring roles during the lock down period when schools and nurseries closed. Caring responsibilities would impact on an individual's ability to rest and recuperate, which could delay recovery. It would be wise to look at this variable alongside medical factors when assessing risk factors and consider what support could be made available to enable a patient to rest in these circumstances.
86.	Long Covid Scotland		'4'	'31'	For patients who have been ill since the 'First Wave' and who often felt dismissed by or invisible to healthcare providers, as we tried collectively to understand this syndrome, being able to input their experiences through patient involvement and consultation is a vital part of emotional and psychological recovery, both to be heard and to feel a sense of contributing to ensuring those coming after will experience better care. This needs to feel meaningful and not just lip service. This can also be invaluable input. In business improvement approaches, such as lean management, start from the principle that the front line service user and practitioner are best placed to design the most effective means of delivering a service. Our steering group, and our members, are all committed to collaborating with healthcare providers to develop effective and efficient means of adapting delivery of care to meet the needs of those experiencing Long Covid symptoms.
87.	Long Covid Scotland	EAI	''	''	Both Zoe APP data and support group demographics suggest that significantly more women than men (in the range between 70:30 and 60:40) are presenting with prolonged Covid symptoms. Also as evidence exists that more women than men have been primary carers in the home, this factor could impact the ability to rest and recuperate while suffering from covid symptoms and would be a relevant factor to include in research.
88.	Long COVID Scotland	Scope	general	general	Long Covid Scotland are the Scottish off-shoot of Long Covid Support, which has over 28K members living with Long Covid. We campaign for patient involvement in both medical and research settings in Scotland, and so it was heartening to hear that SIGN, NICE and RCGP are keen to consider the lived experiences of patients. Today, our colleagues at Long Covid Support alerted us to the draft scope for the Long Covid guidelines. We made contact with you to our offer input, and you kindly agreed. Unfortunately, the guidelines did not

ID	Stakeholder	Document	Page no.	Line no.	Comments
					come through. We hope you will instead consider the comments in this letter, on behalf of the patients we represent. Inequities based on test/hospital status Not being tested, or testing negative in either antigen and antibody tests, and/or not being hospitalised, can count against patients with Long Covid. It's important to note that the line between hospitalised and non-hospitalised patients may be blurred, especially given the bar for admission to hospital seemed to be higher during the early months of the outbreak. Misdiagnosis While some practitioners are sympathetic, patients often describe being misdiagnosed with anxiety, or told they are well because their tests are clear. This is a common medical bias, noted more by Scottish patients, and frequently described by women 1,2,3. While anxiety may be present, it is important to note this is not the driving cause of Long Covid, and could be a dangerous misdiagnosis for those with cardiac damage, which is common even in non-hospitalised patients 4. Naming of the condition Patients strongly prefer the term Long Covid 5. Terms like 'Post-Covid Syndrome' present inaccuracies, implying the main illness is 'over', despite many feeling much more unwell at 6 months than in the initial weeks. Persistent infection is also still a possibility that is yet to be ruled out 6. The terms 'post' and 'syndrome' carry a long legacy of stigma, and so we ask they are not used. Symptoms and timescales It is, of course, the nature of guidelines to boil symptoms and timescales down, however, given Long Covid is so new and variable, this may prove problematic for some patients. Long Covid symptoms, timescales, and experiences vary greatly. Some experience a relapsing and remitting condition, as opposed to a more linear one. We hope these comments are useful, and we'd be happy to discuss them further. We also look forward to inputting at the next stage, where we can go into more detail about the experiences of Scottish patients. References 1. Sex Matters: How male-centric medicine endangers women's health and what we can do about it https://books.google.co.uk/books/about/Sex_Matters.html?id=H2e2DwAAQBAJ&redir_esc=y

ID	Stakeholder	Document	Page no.	Line no.	Comments
					2. Doing Harm: The Truth About How Bad Medicine and Lazy Science Leave Women Dismissed, Misdiagnosed, and Sick https://books.google.co.uk/books/about/Doing_Harm.html?id=He-mDAAAQBAJ&redir_esc=y 3. Katz Institute for Women's Health: Gaslighting in women's health: No, it's not just in your head https://www.northwell.edu/katz-institute-for-womens-health/articles/gaslighting-in-womens-health 4. Outcomes of Cardiovascular Magnetic Resonance Imaging in Patients Recently Recovered From Coronavirus Disease 2019 (COVID-19) https://jamanetwork.com/journals/jamacardiology/fullarticle/2768916 5. Why we need to keep using the patient made term "Long Covid" https://blogs.bmj.com/bmj/2020/10/01/why-we-need-to-keep-using-the-patient-made-term-long-covid/ 6. COVID Immune Responses Explained https://www.medscape.com/viewarticle/933621#vp_3
89.	Long Covid Support		'General'	'general'	We welcome the development of a NICE guideline and would like to thank the committee for initiating it. It will be welcomed by people with Long Covid who are currently struggling with the condition and suffering a great deal of morbidity. There is a perception amongst patient groups that finding good care for Long Covid is hit and miss. Those of us who are working with our GPs to navigate the system perceive that GPs are also in need of, and would welcome, guidance. We are all attempting to learn to manage a complex condition in real time with little to no research findings to guide management.
90.	Long Covid Support		'1'	'24'	I'm not sure what the need is for an intermediate stage called 'ongoing symptoms' and why 12 weeks? It seems to be a number plucked out of thin air. It doesn't obviously relate to patients' experiences.
91.	Long Covid Support		'2'	'1'	'Post covid syndrome'. We would argue strongly against the use of this term, and propose that the term Long Covid is used instead. Many patients don't feel that they are 'post' anything as they feel that Covid never really went away. It also implies that the acute phase is more severe and this is not always the case, some people have worse symptoms in the ensuing months than they did in the acute phase. We would strongly resist any attempts to call the post-acute phase of covid by any other name than Long Covid. Long Covid is a term that has been proposed and adopted by patients because it fits with our experience. We debate these things amongst ourselves in our facebook group of 28 thousand people and there is broad agreement that post-covid is strongly disliked. We object to the medical establishment

ID	Stakeholder	Document	Page no.	Line no.	Comments
					imposing a name on our illness when we were the ones to first recognise our own illness and bring it to the attention of the wider world and we gave it a name that has meaning for us. We would like the medical establishment to take our lead on this and use our preferred term.
92.	Long Covid Support		'2'	'1'	Why does ‘post-covid syndrome’ only refer to new symptoms? Many patients have the same symptoms either continuing or recurring well after 12 weeks.
93.	Long Covid Support		'1/2'	'general'	There seems to be an assumption that you get an acute illness for a few weeks which gradually fades away over 12 weeks, then new symptoms occur which can be described as post-covid. I don’t know where this notion comes from because it doesn’t relate to the patient experience and I don’t understand why there is a perceived need to segment Long Covid up into intermediate stages. It also presupposes some kind of linear progression and completely ignores the relapsing-remitting nature of the illness as experienced by many patients. My own personal experience, and I’m not alone, is that by 12 weeks I thought I was done with it and was merrily telling people I was recovering. I then had a relapse which was worse than the acute phase. Over the 5th and 6th month, I again thought I’d recovered then relapsed again in the 7th month. (nb it was definitely not reinfection, I had no route for reinfection as we were still in lockdown for the first relapse, and in the second the household member who was the only possible vector tested negative). All of my symptoms have been the same, I have not had any new ones. I use my own case as an example but want to stress that I am here to represent the experiences of a large body of patients and my experience is not unique. Not everyone gets new symptoms. I think if you asked 100 patients to describe the course of their illness you will get 50 different descriptions. This guideline scoping is in danger of oversimplifying a complex illness, for what purpose we’re not exactly sure. Why can’t you just say that some people get Covid and don’t recover for a long time, so far of indeterminate length? There is a danger that by imposing a pattern on the scope, you impose a pattern on the illness, and people who do not fit the pattern will be marginalised. This leads to stigma and people are already suffering from being told their illness is caused by anxiety because the world has been anchored to the belief that you either die or get better in two weeks. I understand completely that this is not the intention, and that many practitioners will listen to the patient, and take it as it is presented without trying to impose a model on it. But you must recognise that such good practice is not universal, and that the 12 week thing will inevitably turn into a stick to beat patients with. Not just by some practitioners but by employers and friends and family, who, it may or may not surprise you to learn, are not universally sympathetic or understanding. I can guarantee you that as soon as you start saying that an illness conforms to a pattern, then you create stigma for people who do not conform to that pattern. Given that it’s not clear that the model you propose is even correct, and it’s not clear to us what the point

ID	Stakeholder	Document	Page no.	Line no.	Comments
					of it is in terms of patient benefit, it would seem to have risks with no benefit and we would call for it to be dropped on that basis.
94.	Long Covid Support		2'	'8-11'	You have said that the term post-covid is not to assume that the illness is over but recognises that the acute phase is over. In which case, why use the word 'post'? The general understanding of this word is to mean that something has passed. If you don't want people to assume that covid has passed then please don't use a word which means 'passed'. Whatever the intentions, this will come to mean that the illness is over. GPs won't go back to the guidelines to see your definition, they will just hear the word 'post' and assume that it means that Covid is over. So will the general public. This is another reason why Long Covid is the preferred term.
95.	Long Covid Support		'4'	'22'	I am concerned that there is no mention of the need to understand the relapsing-remitting nature of many cases of Long Covid. This is one of the most common themes amongst our patient group of 28 thousand people. It is imperative that we try to understand what causes relapses and how they can be avoided and managed. I have been having viral respiratory illnesses, like everyone else, for my whole 50 years of life. I have never before had something where specific symptoms, not just general malaise or fatigue, came back weeks after I've ostensibly recovered from it. Patients express bewilderment and distress at the recurrence of symptoms and find it difficult to conduct their lives normally for fear of provoking a return to a state in which they cannot conduct their usual activities. Some people don't have a relapsing-remitting course, rather they have continuing symptoms which may vary in severity but never really remit. It is equally important to understand why some do and some don't relapse and remit as it may speak to underlying etiology.
96.	Long Covid Support		'general'	'general'	If I understand correctly, there is an assumption from the guideline scoping writers that Covid may take time to recover from and 12 weeks has been chosen as a reasonable time frame to get over a serious viral illness during which time there's not much that can be done beyond rest and recuperation. My assumption may be wrong here but that's the impression I got. I think the danger here is that patients will end up being told that they should wait for 3 months to see if it gets better and only come back if it lasts longer. We would rather, for the moment, describe two phases, acute and Long Covid and leave it like that without putting a time-frame on a putative intermediate stage. When good quality evidence is forthcoming, this can be revised, but for now I am unhappy with shoehorning it into this framework, simply because that's how previous post viral illnesses have been described.
97.	Long Covid Support		'4'	'31'	We particularly welcome the section on Lived Experience of patients. There is already a wealth of untapped knowledge within large patient support groups. Patient groups have spearheaded the

ID	Stakeholder	Document	Page no.	Line no.	Comments
					collection of data from within themselves, some of which have already been published. There is a desire to contribute to research within groups and a strong feeling that we have learnt a lot from each other and we would like that learning to be captured and formalised. We would emphasise the importance that knowledge from such research is included in guidelines.
98.	Long Covid SOS	Scope	1	8	Is there any reason the patient-coined term "Long Covid" cannot be used?
99.	Long Covid SOS	Scope	1	23	Is it now accepted that Covid-19 lasts 3-4 weeks and this can be the 'acute' phase?
100	Long Covid SOS	Scope	1	25	Does this mean that a patient can only be classed as suffering from Long Covid after 12 months?
101	Long Covid SOS	Scope	2	10	How do we distinguish between acute covid and long covid? Is it after the 12 weeks have passed?
102	Long Covid SOS	Scope	2	10	We have anecdotal evidence that some patients suffer from asymptomatic covid and then go on to have Long Covid. Is this taken into account?
103	Long Covid SOS	Scope	2	18	The first 12 weeks of the Long Covid illness are usually the most confusing, scary, and demanding of all. Patients have been bounced between 111, GPs, and A&E. Appropriate management should be in place during this period.
104	Long Covid SOS	Scope	2	22	Not all patients are hospitalised and has appropriate tests and diagnostics at this point.
105	Long Covid SOS	Scope	3	3	It's worth noting that children and young people might present differently and could benefit from other specialists taking a part in their treatment.
106	Long Covid SOS	Scope	4	8	What is the prevalence of LongCovid between hospitalised and self-managing patients in the community?
107	Long Covid SOS	Scope	4	8	Does the fact that investigative tests aren't carried out or access to treatments during acute covid make it more likely that someone will go on to develop LongCovid?
108	Long Covid SOS	Scope	4	17-18	This implies no investigations will be carried out before 12 weeks from infection - 3 months is too long to wait when suffering debilitating symptoms, investigations are needed sooner for those with symptoms suggestive or organ or neurological damage
109	Long Covid SOS	Scope	4	22	What early interventions can prevent the development of post-COVID-19 syndrome or potentially decrease the period of ill-health?
110	Long Covid	Scope	5	1-4'	These are vital to understanding what works and what doesn't.

Management of the long-term effects of COVID-19

Targeted peer consultation on draft scope comments table

23/10/2020-27/10/2020

ID	Stakeholder	Document	Page no.	Line no.	Comments
	SOS				
111	Long Covid SOS	Scope	5	10-11'	How will it be ascertained if someone has ME/CFS rather than Long Covid?
112	Long Covid SOS	EIA	general	general	It is important not to assume prevalence/severity of Long Covid across different demographics is similar to prevalence/severity of acute COVID-19 across different demographics. Though solid data is hard to come by, this is almost certainly not the case.
113	NHS England	Scope	General	General	Is the syndrome not a complex of symptoms and signs (may wish to add in results of diagnostic findings) that occur or persist beyond the normal period of recovery that for most viral infections would be around 12 weeks post acute episode
114	NHS England	Scope	General	General	Is the syndrome not a complex of symptoms and signs (may wish to add in results of diagnostic findings) that occur or persist beyond the normal period of recovery that for most viral infections would be around 12 weeks post acute episode
115	NHS England – specialised commissioning	Scope	'general'	''	The definition of the 3-4 week interval after the start of the acute infection. How does this sit with people who end up in ACC and/or on ECMO where there hospital stay might easily result be a 3-4 week duration. Would all those people have long Covid symptoms or still be classed as acute?
116	NHS England and NHS Improvement	Scope	'1'	'17'	Need to explain somewhere in intro about long covid and how that is different to covid syndrome. we need to move away from the former
117	NHS England and NHS Improvement	Scope	'1'	'22'	"Symptoms experienced in the first 3 to 4 weeks from the start of COVID-19 infection". Need to clarify whether this refers to the start of a time period of confirmed infection (i.e. diagnosed infection) or a time period that may also include clinical symptoms of infection that are not formally diagnosed. Bearing in mind later it states that people can diagnose retrospectively (see line 13, Page 2)
118	NHS England and NHS Improvement	s	'1'	'23 & 26'	Suggest use the term "Symptoms and signs". (Symptoms may only be found on measurements eg nocturnal or exercise desaturation)
119	NHS England and NHS Improvement	Scope	'2'	'1'	Worth saying that Post-COVID-19 syndrome may turn out to be range of different diagnoses as more information emerges?
120	NHS England and NHS Improvement	s	'2'	'2'	New symptoms, signs or findings at 12 weeks are unusual. Most are ongoing

Management of the long-term effects of COVID-19

Targeted peer consultation on draft scope comments table

23/10/2020-27/10/2020

ID	Stakeholder	Document	Page no.	Line no.	Comments
121	NHS England and NHS Improvement	Scope	'2'	'3'	"continue for more than 12 weeks". Does this refer to symptoms that continue beyond the 12 week period that is previously classified within 'ongoing symptomatic COVID-19)? It is not clear to me whether POST COVID can be defined at any time beyond the acute phase according to this.
122	NHS England and NHS Improvement	Scope	'2'	'6-7'	Too vague: post covid but still have ongoing covid. Clarification required to avoid confusion
123	NHS England and NHS Improvement	Scope	'2'	'9'	First time "signs" term appears
124	NHS England and NHS Improvement	Scope	'3'	'3'	As this guideline covers adults and children who are in work and school, practical tips for employers and schools to support their employees/children could also be helpful.
125	NHS England and NHS Improvement		'3'	'3-5'	Syndrome is now 3-4 weeks. inconsistent with comments on page 1
126	NHS England and NHS Improvement	Scope	'3'	'19'	Ref to ongoing care: worth also highlighting need to refer if suspecting other conditions or is aim that anything non urgent will go to a designated long COVID clinic for assessment and referral onwards as needed?
127	NHS England and NHS Improvement	Scope	'4'	'1'	Ensure the order of the themes reflects progression through patient experience from initial assessment onward. Add a separate section on presentation/signs and symptoms of post-COVID-19 syndrome (with the caveat that the list is not exhaustive as we continue to learn more). Add a section on case finding. Not everyone with post-covid syndrome may be known to services depending on where/how their illness was managed Also look at barriers to presenting/patient awareness of symptoms.
128	NHS England and NHS Improvement	Scope	'4'	'8'	Add bullets to include investigation and assessment: History e.g. key red flags to consider Basic diagnostics/ investigations to include for all Physical assessment: signs on examination to look out for

Management of the long-term effects of COVID-19

Targeted peer consultation on draft scope comments table

23/10/2020-27/10/2020

ID	Stakeholder	Document	Page no.	Line no.	Comments
					Differential diagnosis to ensure distinguishing other conditions both in assessment and investigation and avoid delay in management Might need to consider whether we describe it as a ‘diagnosis of exclusion’ in order to avoid missing other pathologies? (An analogy might be the diagnosis of irritable bowel syndrome whereby a basic set of blood tests are always done to exclude something more serious) Include exclusion criteria
129	NHS England and NHS Improvement	Scope	'4'	'8'	Clarity about different presentations in adults versus children would be helpful.
130	NHS England and NHS Improvement	Scope	'4'	'19'	Specialist is a confusing term. For example “specialised commissioned service”: is a community IAPTs service seen as specialised? Either define term or use an alternative
131	NHS England and NHS Improvement	Scope	'4'	'23'	Define the assessments before you consider this is covid syndrome and consider treatment
132	NHS England and NHS Improvement	Scope	'4'	'29'	Opportunity for integrated and personalised approaches – e.g. clinical networks; integrated service delivery across sectors and disciplines; use of community assets
133	NHS England and NHS Improvement	Scope	'5'	'7-8'	Need to really think about timings. they seem to vary in scope. Hospital discharge difficult as many not admitted
134	NHS England and NHS Improvement	EIA	'3'	'Multiple'	Important to highlight the potential impact of racism on interactions with the healthcare system, feel this also applies to the stigma that people may feel based on their religion/belief (e.g. Islamophobia, overlaps often with racism), sexual orientation and socio-economic status.
135	NHS England and NHS Improvement	Scope	'General'	''	Not sure how it is possible to exclude and control for ‘general’ Post Intensive Care syndrome in those who have been cared for in ICU due to COVID-19.
136	NHS England and NHS		''	''	If Children and young peopel affected (aware of some cases), would advocate close links with schools, universities as extra support may be required to maintain educational attainment.

ID	Stakeholder	Document	Page no.	Line no.	Comments
	Improvement				
137	NHS England and NHS Improvement		"	"	Burden of Long Covid likely goes way over 12 weeks and is likely to be over 12 months or even a long-term condition.
138	NHS England and NHS Improvement		"	"	Recognition needed for variable symptomatology as is often the case in long-term conditions and different presentations – noting a need for caution in being to quick to lock down a definition / diagnostic criterion.
139	NHS England and NHS Improvement		"	"	Is there an opportunity to advocate the joining up of services who deal with specific presentations – e.g. fatigue whether induced by Chronic fatigue symdrome or COVID? Breathlessness whether COVID or A.N.Other clinical diagnosis? To avoid duplication and ensure we use the skills of the workforce most effectively
140	NHSE/I	Scope	'1'	'17'	Does the case definition only apply to people who are PCR positive for acute or ongoing COVID (I can see the diagnosis can be clinical for post COVID syomptoms)
141	NHSE/I	Scope	'5'	'9'	It would be helpful to have some guidance about how to distinguish patients with Post COVID syndrome from those with ME/CFS
142	NHSE/I	Scope	'4'	'22'	Could we explicitly consider the role of online resources and virtual consultations given the ongoing pandemic.
143	NIHR Centre for Engagement and Dissemination	Scope	'2'	'1'	It is not clear that these symptoms are 'post Covid' – some suggest that they may be due to low level continuing viral activity. Given the mild initial infections some people with lingering problems have, and the absence of community testing in the Spring, it can be difficult to date the initial infection precisely. It is unclear what benefit this third time classification will provide in determining diagnostic and treatment/support pathways and may delay active management
144	NIHR Centre for Engagement and Dissemination	Scope	'2'	'9'	This assumes a linear pathway with acuity subsiding over time. Our review found many people who were not admitted to hospital have a) fluctuating acuity and b) higher acuity some weeks after the initial infection
145	NIHR Centre for Engagement and	Scope	'2'	'12'	We strongly support this

Management of the long-term effects of COVID-19

Targeted peer consultation on draft scope comments table

23/10/2020-27/10/2020

ID	Stakeholder	Document	Page no.	Line no.	Comments
	Dissemination				
146	NIHR Centre for Engagement and Dissemination	Scope	'4'	'1'	Our review found many people are severely debilitated and in need support of with activities of daily living and managing their own health. We suggest a 6th theme on this (also includes financial support for those unable to work)
147	NIHR Centre for Engagement and Dissemination	Scope	'4'	'22'	Our review found many people would like a case manager/key worker to coordinate their care
148	NIHR Centre for Engagement and Dissemination	Scope	'4'	'32'	We have a survey running of our website that asks people with lived experience of ‘Long Covid’ about access to services by nation. As of 24th October there are more than 3000 responses.
149	NIHR Centre for Engagement and Dissemination	EIA	'No page numbers given'	'1.2'	We are concerned that seldom heard voices, such as the homeless, prison populations and traveller communities have been excluded from discussion and research to date. We note evidence of Long Covid in Care Homes
150	NIHR Centre for Engagement and Dissemination	EIA	'No page numbers given'	'1.3'	Stakeholders from seldom heard voices listed above should be consulted
151	Individual – Derek Wade	Scope	general	general	General. As the scope is written, I would foresee endless discussion and arguments within the group, and equally endless disagreements with and discussions about any guidance written, because of the difficulty of drawing any lines around any of the definitions, and especially the exclusions. I cannot see how you can draw any clinical, conceptual or other logical difference between the syndrome, and the areas that you

ID	Stakeholder	Document	Page no.	Line no.	Comments
					are deliberately excluding such as chronic fatigue syndrome or post intensive care syndrome. Syndromes, by their very definition, have many symptoms which may have many causes, and there is no way to draw lines around them.
152	Individual – Derek Wade	Scope	general	general	General (definition) It is unclear to me whether the syndrome does or does not include symptoms that were or might have been present in the acute infection. It states "new symptoms that develop following an infection …. continue for more than 12 weeks, and not explained by an alternative diagnosis." Does this mean that the symptom cannot have been present in the acute phase? If a person has breathlessness in the acute phase, and continues to have breathlessness at 12 weeks associated with many other symptoms such as anxiety and fatigue, then is that part of the syndrome or is it attributable to end organ damage? And how can you tell when there is probably little connection between the apparent extent of damage or change on imaging studies and a person's symptoms.
153	Individual – Derek Wade	Scope	2	8-9'	I do not think that your rationale (page 2 line 9) is going to be sustainable. How long is the acute phase? How is it defined as being resolved? If you accept that there is some form of active continuing disease process occurring, then it is not a post Covid syndrome, it is chronic Covid infection.
154	Individual – Derek Wade	Scope	general	general	General (definition) My personal view is that you would be much better simply stating that if a person has any symptoms 12 weeks after the onset of symptoms of infection that were not present before the onset of the infection, then they fall into this guideline. This will exclude people who simply have the same symptoms as before, provided they have no new symptoms.
155	Individual – Derek Wade	Scope	general	general	General (scope, functional illness). A further problem is that you have not mentioned the word, functional illness. This is naïve. 25% of all hospital attendance is attributable to functional illness, and there is no reason to believe that people who have had Covid are immune to functional illness. There will be a significant number of people whose primary problem after Covid is functional, however that is conceived.
156	Individual – Derek Wade	Scope	4	10-11'	On page 4, line 10 you draw a distinction that is not possible. You refer to symptoms as being physical and psychological as if these were two completely separate categories. I can have symptoms of tingling in my fingers, which could be considered physical, but it could be entirely due to anxiety or distress which is psychological. On the other hand I could have extreme anxiety and palpitations where the palpitations might be considered a manifestation of anxiety, whereas in fact the anxiety is secondary to the palpitations and arises as a direct result of a raised pulse rate.

ID	Stakeholder	Document	Page no.	Line no.	Comments
157	Individual – Derek Wade	Scope	4	29	On page 4 line 29 you refer to a "service model" as if it was likely that there would be a single service. I think it is obvious that the range of problems is large, and they frequently overlap, and that there will be no common single group warranting a particular service. It would be counter-productive to have a service for people with a particular syndrome given that the syndrome covers almost everything. The issue to be addressed is how to get the disorganised separate services that people will need to work as a collaborative whole so that a person who has considerable respiratory problems, with additional fatigue and poor sleep and poor memory, and perhaps an incidental neuropathy arising from prone lying causing a brachial plexus lesion manages to have a coherent single service which, given the current lack of any organisational principles behind service delivery, would be impossible. Inventing a new service simply means repeating exactly the services that exist only in one place. It would be simpler for the services that exist to work together to meet the needs of individual patients.
158	Individual – Derek Wade	Scope	5	6-11'	On page 5, line 6 to 13 you exclude some groups. What about patients who have had a small stroke with weakness and reduced dexterity in the dominant hand, probably insufficient to be accepted by a stroke service given the pressure on their service, and who also has respiratory problems from long-standing chronic obstructive pulmonary disease exacerbated markedly by the respiratory infection of Covid, and a degree of anxiety due to post-traumatic stress disorder or post intensive care syndrome? Will they be excluded? On what rational grounds? They have problems arising after Covid.
159	Individual – Derek Wade	Scope	general	general	General In summary, “I would not start from here!” I think that the fundamental assumptions underlying this proposal need to be reviewed, and it should be placed within the biopsychosocial model of illness which makes it clear that individual symptoms cannot be and should not be considered in isolation nor do any individual symptoms necessarily have the same causes in different patients.
160	Patient Safety Learning	EIA		1.2	There is a risk that longcovid symptoms will be incorrectly seen as a symptom of an underlying condition; this may be as consequence of an age, race or sex bias
161	Patient Safety Learning	EIA		1.2	There is a risk of physical symptoms of longcovid being dismissed as anxiety or psychological illness; this may be as a consequence of an age, race or sex bias
162	Patient Safety Learning	EIA		1.2	‘There are known differences in terms of poorer outcomes from COVID-19 for men compared to women, so it is important to consider potential differences in clusters of symptoms when drafting

Management of the long-term effects of COVID-19

Targeted peer consultation on draft scope comments table

23/10/2020-27/10/2020

ID	Stakeholder	Document	Page no.	Line no.	Comments
					recommendations.' There is also some research evidence of women being affected more by post-COVID 19
163	Patient Safety Learning	Scope		8	The guideline may be of use to: • Local authorities and social care providers who may need to support people with post-COVID 19 in the community • Employers to understand that employees with post-COVID 19 have long term legitimate illnesses
164	Patient Safety Learning	Scope		32	Should include parents for children under 18. Also, carers/guardians and family members
165	Patient Safety Learning	Scope		32.5	Include patients' views on advice and guidance available/provided
166	Patient Safety Learning	Scope	key themes	1.7	Advice and guidance to patients: • On the disease • Prevalence • Management and rehabilitation
167	Professional Advisory Group, Clinical Guidance Cell, Scottish Government	EIA	'General'	'general'	I am sorry that I am late in my response to you. I hope you can accommodate my late comments if possible. These are related to EQIA (in the second PDF document) and examples of other definable characteristics. In the EQIA, it would be helpful to clearly state whether mobile populations such as Gypsy/Travellers will be included or excluded and the reasons for exclusion. The examples in definable characteristics could also include "mobile populations" such as Gypsy/Travellers, Armed Forces personnel, etc., in addition to the homeless, migrant workers, asylum seekers and refugees.
168	Individual (and member of	Scope	'General'	'General'	"Post-COVID-19 syndrome" is an unhelpful term. I would prefer "post-acute and chronic COVID-19" or "the long-term effects of COVID-19" for the following reasons:

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.

ID	Stakeholder	Document	Page no.	Line no.	Comments
	Long COVID Support)				Consistent with previously published medical literature (Greenhalgh et. al) https://www.bmj.com/content/370/bmj.m3026 The symptoms fluctuate, and new symptoms (that are known to appear in patients acutely such loss of sense of smell) emerge late on in the course of the illness.1 Immunologists such as Prof Iwasaki have suggested the possibility of viral persistence as a cause of this condition. https://www.medscape.com/viewarticle/933621#vp_3. Calling the condition "POST-COVID-19 syndrome" serves to imply, with an unwarranted degree of certainty, that the disease process has finished, whilst the terms "post-acute and chronic COVID-19" or "the long-term effects of COVID-19" serve to make no assumptions about the underlying biological mechanisms at play, and therefore are most consistent with a "living approach" to the guidelines, uncertainty and emerging evidence which is a very welcome and essential philosophy. It is most consistent with the term that people living with the condition are using, i.e. "Long COVID", further arguments made here: https://blogs.bmj.com/bmj/2020/10/01/why-we-need-to-keep-using-the-patient-made-term-long-covid/ [70% of the respondents selected "new symptoms appeared at different times." in this patient led research study https://patientresearchcovid19.com/research/report-1/#Highlights_from_the_Survey_Analysis as well as from my personal experience and personal correspondence with others]
169	Individual (and member of Long COVID Support)	Scope	'1'	'19'	Should say "COVID-19" or "SARS-CoV2 infection". Not "COVID-19 infection"
170	Individual (and member of Long COVID Support)	Scope	'1'	'23'	Should choose between 3 or 4 weeks to avoid confusion? Again Greenhalgh et al used "acute" to describe symptoms up to 3 weeks. Again should say "COVID-19" or "SARS-CoV2 infection". As COVID-19 is the disease it would be easier to define from 3 weeks after the first symptoms of COVID-19, whereas date of infection with SARS-CoV2 will be difficult to establish.
171	Individual (and member of Long COVID	Scope	'1'	'24'	Whilst the term "Ongoing symptomatic COVID-19" feels generally acceptable, I cannot see what it offers above "post-acute COVID-19" and does mean that another new term has been introduced which will serve to confuse the terminology further?

ID	Stakeholder	Document	Page no.	Line no.	Comments
	Support)				
172	Individual (and member of Long COVID Support)	Scope	'2 '	'1 '	Please see rationale above re: disagreement with term “Post-COVID-19 syndrome”
173	Individual (and member of Long COVID Support)	Scope	'2'	'4'	I’m confused by what the term “often overlapping” means. I think this needs clarification.
174	Individual (and member of Long COVID Support)	Scope	'2'	'8-11'	“This does not assume that the COVID-19 illness is over but recognises that the acute illness has usually ended.” Using the term “Post-COVID-19” does imply that COVID-19 illness is over. Chronic COVID-19 avoids this, or if the term is intended to imply that the acute illness has ended, then the term needs to add that qualifier, e.g. “Post-acute COVID-19 syndrome”? Can it also be made explicitly clear that this affects individuals that were never admitted to hospital?
175	Individual (and member of Long COVID Support)	Scope	'2'	'22'	Can any references be given for “aligns with 21 other related guidance on appropriate follow-up and discharge
176	Individual (and member of Long COVID Support)	Scope	'2'	'23'	Can endocrine be added here. https://pmj.bmj.com/content/96/1137/412
177	Individual (and member of Long COVID Support)	Scope	'2 '	'29'	I couldn’t access the “exclusions”, would be interested to see
178	Individual (and member of Long COVID Support)	Scope	'3'	'5'	Use COVID-19 symptoms, not COVID-19 infection

ID	Stakeholder	Document	Page no.	Line no.	Comments
179	Individual (and member of Long COVID Support)	EIA	'1'	'1.1'	I would like to suggest that the proposed primary focus of the guideline is a population with a specific communication or engagement need, related to e.g. disability. Many people living with these symptoms are finding it very difficult to think and concentrate and so may need more time than usual to consult. See: https://www.medrxiv.org/content/10.1101/2020.10.20.20215863v1.full-text People may have limited mobility and ability to attend multiple appointments etc. due to their symptoms. Apart from considering additional time for consultation I'm not sure what else should be changed, but might be prudent to acknowledge this in the EIA.
180	Individual (and member of Long COVID Support)	Scope	'4'	'1'	Key themes: Wondering whether the intersection with "test and trace" can also be relevant to the guidelines, such as a need for people to be phoned 4 and 12 weeks post positive test to be asked if they are recovered? Wonder if a "national registry" of people living with the long-term effects of can be included/recommended? Wonder if the guidelines can make further recommendations on research gaps etc?
181	Royal College of General Practitioners	Scope	'1'	'23'	"Experienced in the first 3-4 weeks.." Can the committee consider using 4 weeks to make the scope clearer? The cut off between acute and on-going covid-19 appears arbitrary as the disease is an ongoing spectrum. Using 4 weeks or 28 days would better and would not stop primary care investigating these patients sooner if needed.
182	Royal College of General Practitioners	Scope	'2'	'6'	We agree with the 12 weeks to formal diagnosis of "post covid 19 syndrome" From a trauma perspective, 12 weeks fits with the time you are likely to find pathological changes rather than symptoms that will recover, and 12 weeks gives time for those who will naturally recover to do so.
183	Royal College of General Practitioners	Scope	'3'	'3'	Can consideration be made to a separate guidance for those under the age of 18 in collaboration with the RCPCH? Children are physiologically different to adults and if they are to be included in this guidance will need a separate section to ensure their needs are fully taken into account.
184	Royal College of General Practitioners	Scope	'4'	'17'	The evidence base for 'Long covid' is only just emerging. The use of the term "should" is usually reserved when based on strong evidence. Can the committee consider using "..could be carried out…" rather than should.

Management of the long-term effects of COVID-19

Targeted peer consultation on draft scope comments table

23/10/2020-27/10/2020

ID	Stakeholder	Document	Page no.	Line no.	Comments
185	Royal College of General Practitioners	Scope	'4'	'17'	Can the committee consider separating the primary and secondary care pathway for investigation? e.g. "What investigations could be carried out in primary care prior to referral for further investigation or treatment" "What investigations could be carried out in secondary care….."
186	Royal College of General Practitioners	Scope	'5'	'5'	An additional key question must include research. Can the committee consider adding "What are the gaps in the current research available to determine the best evidence base for care of post covid syndrome". This will enable future research to be designed and commissioned based on the guidance.
187	Royal College of General Practitioners	Scope	'5'	'6'	Exclusions: Is there a date before which the diagnosis of Post Covid syndrome cannot be made? There may be some patients who had a flu or other illness in December 2019, or before, that have ongoing symptoms and look for a diagnosis of post covid syndrome. If evidence shows that COVID-19 was in the UK from approximately January 2020, consideration should be given for an exclusion relating to onset of symptoms E.g. January 2020 for onset and March 2020 for Post covid syndrome.
188	Royal College of General Practitioners	Scope	'6'	'1'	Related NICE Guidance and Overlaps. All cited documents apply to adults over 18. If this new guidance applies to children, then these overlaps could be reasonably disputed unless paediatric specific guidance is considered.
189	Royal College of General Practitioners	EIA	''	''	We are very pleased to see that socio-economic deprivation is included in the EIA given the strong links between increased morbidity and mortality from Covid with higher levels of poverty. It is really important to have explicitly acknowledged. Thank you.
190	Royal College of Nursing	EIA	'Page 3'	''	under the definable characteristics a group perhaps add those who have been trafficked Under the EIA for religion & belief I wonder if some of the data linked to race could be reflected here, though it is not unusual for this section to be missed in completing patient assessments and so therefore limited data for analysis. Under Socioeconomic factors: Could this be strengthened. Social deprivation has a much larger impact on health outcomes than

ID	Stakeholder	Document	Page no.	Line no.	Comments
					merely “accessibility to health care resources”. Our understanding is that there is emerging evidence of a link between social deprivation and incidences of Covid-19 that needs to be explored more fully.
191	Royal College of Nursing	Scope	''	'general'	as this is to be an agile document going forward what will be the process for regular updating and who will be involved
192	Royal College of Nursing	Scope	'4'	'15 & 25'	Need to add school due to CYP being in the scope.
193	Royal College of Nursing	EIA	'General'	'General'	Would be useful to see some kind of intersectional analysis (where the outcomes for those with more than one protected characteristic are particularly concerning e.g. older BAME men who experience socio-economic deprivation)
194	Royal College of Physicians		'general'	'general'	The RCP is grateful for the opportunity to respond to the above. We would like to endorse the responses submitted by the British Thoracic Society (BTS), British Society for Allergy and Clinical Immunology (BSACI), and British Infection Association (BIA).
195	Royal College of Physicians and Surgeons of Glasgow, Clinical Cell	SCOPE	'General'	'General'	Generally, the College is very happy with this document. It is timely and good advice on available evidence is required in this emerging problem. The case definitions are not going to look at acute COVID (although they may have to look at various characteristics of the acute illness to see if they predispose to post COVID). We believe that for 3-4 weeks to 12 weeks is recovering acute COVID rather than a separate entity. We consider the review should concentrate on symptoms continuing after 12 weeks but be flexible. These may include new symptoms developing and also existing symptoms such as loss of sense of smell and taste. There are parallels with Gulf War Syndrome and what is important is that we listen to patients. Although the paper has mentioned exclusions such as ME, Chronic fatigue or fibromyalgia etc, there may be special features of this syndromes (which are defined by vague symptoms which are pertinent to Post COVID syndrome. A n open mind needs to be kept
196	Royal College of Physicians and Surgeons	EIA	'General'	'General'	The equality assessment includes homeless people, health workers and those of BAME background (although there was a report last week suggesting the increased risk were related to comorbidities, obesity, and social and work environments. No evidence for this was produced and this is different to the

ID	Stakeholder	Document	Page no.	Line no.	Comments
	of Glasgow, Clinical Cell				NHS England paper we have previously seen). We commend this as it is very pertinent.
197	Royal College of Physicians and Surgeons of Glasgow, Clinical Cell	Scope	'2'	'13'	Diagnosis includes those that thought they had COVID based on likely self-reported symptoms. This means that any ME/CFS symptoms developing since Feb 2020 feature in the definition and therefore the “themes to be excluded” on page 5 is in conflict with this. Appreciating that there will not be a virologically confirmed diagnosis for everyone for obvious reasons, and poor sensitivity of the antigen testing at present there needs to be a more definite virological link for this to be workable and not overwhelmed with a wide array of patients(unless the scope is widened to include CFS/ME!)
198	Royal College of Physicians and Surgeons of Glasgow, Clinical Cell		'4'	'19'	Using terms like “secondary care” may insinuate medical specialties but it is likely that psychological and physiotherapies may be more appropriate and this should be specifically explored.
199	Royal College of Physicians and Surgeons of Glasgow, Clinical Cell		'General'	''	It should be explicit where secondary care services have no role. i.e. there is no evidence base for diagnostic or therapeutic interventions. This is important for 2 reasons namely-avoidance of already overwhelmed secondary care OP services being asked to see patients for whom there is no evidenced based benefit. Secondly for individual patients should not be given false expectations that referral to a secondary service will result in benefit and the practice of honest realistic medicine that is evidenced based should be upheld.
200	Royal College of Physicians and Surgeons of Glasgow, Clinical Cell	Equality	''	''	There is concern that those patients with post viral fatigue/CFS in the pre COVID era with likely very similar symptoms have not had the same investment in services for therapeutic interventions that may be mutually beneficial for both groups, thus causing a 2 tier system depending on the initial insult that may or may not be easily defined.
201	Royal College of Physicians and Surgeons of Glasgow, Clinical Cell	Scope	'1'	'23'	Symptoms experienced in first 4 weeks… is clearer than 3-4
202	Royal College of Physicians	Scope	'1'	'25'	Symptoms experienced more than 4 weeks and up to 12 weeks… otherwise there will be overlap

ID	Stakeholder	Document	Page no.	Line no.	Comments
	and Surgeons of Glasgow, Clinical Cell				
203	Royal College of Physicians and Surgeons of Glasgow, Clinical Cell	Scope	'2'	'6'	I think the definition should start at >12 weeks for reasons above. Symptoms occurring before then may be recognised later as compatible with ‘post covid syndrome’ but in this initial stage having clear time definitions is important
204	Royal College of Physicians and Surgeons of Glasgow, Clinical Cell	Scope	'3'	'4'	More than 4 weeks (not 3-4 weeks)
205	Royal College of Physicians and Surgeons of Glasgow, Clinical Cell	Scope	'4'	'12,13'	3-12 or 4-12 weeks?
206	Royal College of Physicians and Surgeons of Glasgow, Clinical Cell	Scope	'5'	'7'	Less than 4 weeks
207	Royal College of Physicians and Surgeons of Glasgow, Clinical Cell	EIA	'2'	''	Age: mention of children and younger people and those over 65 - it may be helpful to have ‘adults’ or ‘younger adults’ as well
208	Royal College of Physicians	Scope & EIA	'General'	'General'	I have no specific questions or comments.

Management of the long-term effects of COVID-19

Targeted peer consultation on draft scope comments table

23/10/2020-27/10/2020

ID	Stakeholder	Document	Page no.	Line no.	Comments
	and Surgeons of Glasgow, Clinical Cell				
209	Royal College of Physicians and Surgeons of Glasgow, Clinical Cell	Scope & EIA	'General'	'General'	No relevant comments.
210	Royal College of Physicians and Surgeons of Glasgow, Clinical Cell	Scope	'General'	'General'	Scoping document looks comprehensive.
211	Royal College of Physicians and Surgeons of Glasgow, Clinical Cell	Scope	'4'	'8-18'	1)Should the scope include a stated aim to ascertain whether there is any role for diagnostics in identifying cases/case definitions, in addition to informing case management? 2)Should there be a stated aim to refine case definitions and agree reporting pathways so that national datasets can capture consistent information on Long covid?
212	Royal College of Physicians and Surgeons of Glasgow, Clinical Cell	Scope	'General'	'General'	This is a comprehensive and sensible plan.
213	Royal College of Physicians and Surgeons of Glasgow, Clinical Cell	Scope	'General'	'General'	This is a comprehensive and sensible plan.
214	Royal College of Physicians and Surgeons	Scope	'General'	'General'	No comments

ID	Stakeholder	Document	Page no.	Line no.	Comments
	of Glasgow, Clinical Cell				
215	Royal College of Psychiatrists	Scope	'7'	'23 - 28'	Only mention here of psychological or psychiatric impacts is 'associated psychological impacts'. Emerging evidence is showing there are direct psychiatric and psychological impacts as well as secondary associated impacts. More detail and evidence is provided within subsequent comments and attached research.
216	Royal College of Psychiatrists	Scope	'3'	'6 - 7'	Reference on page 3 to subgroups on specific issues developing during the development of the guidelines ignores the available evidence already available on what groups are at heightened risk from acute Covid-19 (a short list below) for whom these subgroups could be based around. Groups needing specific consideration Subject to shielding measures (those with underlying medical conditions such as asthma, COPD, CF, organ failure (kidney, liver, cardiac)) those with associated conditions such as hypertension and obesity immunosupressed individuals (eg transplant recipients)
217	Royal College of Psychiatrists	Scope	'General'	'General'	The Scope overlooks the key influence of mental illness as a comorbid condition and the health inequalities in this group.
218	Royal College of Psychiatrists	Scope	'General'	''	The document should explicitly include the need to consider and manage cognitive problems/ cognitive impairments in the context of Long Covid-19... there is no mention of cognition in the document. That means an important aspect of rehabilitation will be overlooked if not updated. It has been shown that even mild Covid-19 infection is associated with objective cognitive impairment… and effect sizes in those with history of severe infection are large even after recovery from acute Covid-19 symptoms. These will impede functional recovery and have a profound economic cost if not recognised and treated. As well as cognition being central to understanding Covid-19 consequences, the document should also mention the importance of psychometric assessment – see for example 'early experiences of Long Covid-19' shared by the Australian and by the Salpetriere hospitals.
219	Royal College	Scope	'General'	''	"psychiatric symptoms" and "Psychiatry" should be explicitly included in the document - mentioning

ID	Stakeholder	Document	Page no.	Line no.	Comments
	of Psychiatrists				"psychological" is not sufficient due to its different, more circumscribed meaning. Psychiatry encapsulates the full range of mental health disorders and symptoms, including those that can arise by or be exacerbated by Covid-19. Unless such medical specialities (including neuropsychiatry) are included, comprehensive assessments and investigations will not be done; treatment options will be overlooked; and appropriate commissioner investment will not be put in place. In this sense would also highlight the importance of mentioning psychopharmacological treatment options in the document as a type of treatment, i.e. not only psychological treatments.
220	Royal College of Psychiatrists	Scope	'General'	''	It should be noted in the document that diagnosable (and treatable) psychiatric disorders are likely to be risk factors for and perpetuating factors in Long Covid. We would also note the significant experience and expertise in the UK psychiatric community on the management of post-infectious fatigue states and chronic fatigue syndromes.
221	Royal College of Psychiatrists	Scope	'General'	''	Consideration should be given for the role of clinical structured and semi-structured investigative psychiatric and neuropsychiatric tools. For example: WHOSCANv3.0 (2020; WHO Schedules for Clinical Assessments in Neuropsychiatry) Which includes all neuropsychiatric conditions as applicable to the CNS affecting neurological conditions and comprehensively ascertains all neurodevelopmental, and all somatoform conditions, in addition to all the main Psychiatry and Neuropsychiatry (post - stroke, ABI / TBI, epilepsy, infections etc. conditions).
222	Royal College of Psychiatrists	Scope	'General'	''	If recommendations include increased provision of those with psychological or psychiatric symptoms then investment needed for developing and resourcing appropriate treatments should also be taken into account.
223	Royal College of Psychiatrists	Scope	'General'	''	Further highlighting investment needed into psychiatry and neuropsychiatry clinical and bioscience research on definition, mechanisms treatments and consequences, and into the ongoing upskilling and training of the next cohort of academic researchers and educators (i.e. clinical academic psychiatrists), in this emerging area of importance.
224	Royal College of	Scope	'General'	''	The bibliography/reference list should include key papers identifying psychiatric and neuropsychiatric presentations of Covid-19 as well as literature showing cognitive impairment in those who have

Management of the long-term effects of COVID-19

Targeted peer consultation on draft scope comments table

23/10/2020-27/10/2020

ID	Stakeholder	Document	Page no.	Line no.	Comments
	Psychiatrists				recovered from Covid-19, including after acute infective symptoms have resolved. This must include the very preliminary but typically specific meta-analysis (Jan - end April 2020) of psychiatric symptomatologies of previous coronavirus encephalitis (incl the MERS 2012/13 outbreak) by Anthony King's team.
225	Royal College of Psychiatrists	Scope	'General'	''	Although we understand the need to progress with Covid-19 services quickly, we are concerned by the short notice period given to provide feedback, which means the feedback may not be inclusive of all important stakeholders.
226	Royal College of Speech and Language Therapists (RCSLT)	Scope	'2 and 5'	'1 ‘Post Covid-19 syndrome’ (page 5, line 9)'	Please can you clarify whether this guidance will include people with Post Intensive Care Syndrome (PICS) post COVID-19 who have significant rehab needs. It is included in the definition of Long Covid (category A) in the House of Lords enquiry but is excluded in this scope therefore the definition is not consistent. We also do not agree with the exclusion of PICS and think that it should be included. In follow-up clinics, speech and language therapists (SLTs) are seeing patients with long-covid symptoms such as ongoing breathlessness, cough, fatigue, brain fog, anxiety, and depression (and then consequently, voice and swallowing problems). These may be a result of COVID more than ICU intervention or weakness, therefore, our SLT experts are querying why and how can you reliably separate it?
227	Royal College of Speech and Language Therapists (RCSLT)	Scope	' 3, section 3'	' 10'	The document may also be of interest to healthcare researchers who are looking into the 5 areas prioritised in the research agenda (see evidence from the House of Lords enquiry)
228	Royal College of Speech and Language Therapists (RCSLT)	EIA	'2'	''Age’ '	Elderly people with acquired communication impairments or dementia need to be highlighted as vulnerable groups who are unlikely to report symptoms and may need SLT support to facilitate access to care.
229	Royal College of Speech and Language	EAI	' 2'	''Disability''	Communication impairment must be highlighted in addition to hearing, eyesight, and cognitive difficulties.

ID	Stakeholder	Document	Page no.	Line no.	Comments
	Therapists (RCSLT)				
230	Royal College of Speech and Language Therapists (RCSLT)	Scope	'4'	' 8 Investigation and assessment'	We believe this needs to include a review of what screening tools, frameworks and guidelines exist to assess symptoms and functional impairments. This should ensure that the Intensive Care Society (ICS) rehabilitation framework and PICUPS screening tool are highlighted. These then ensure that speech and language therapy and rehab needs are flagged. See link below: - https://ics.ac.uk/ICS/ICS/GuidelinesAndStandards/Framework_for_assessing_early_rehab_needs_following_ICU.aspx
231	Royal College of Speech and Language Therapists (RCSLT)	Scope	' 4'	' 19 'Referral to specialist care''	See point above. We think that this needs to include what referral pathways exist. Not just secondary care in community but also specialist assessment at a tertiary centre.
232	Royal College of Speech and Language Therapists (RCSLT)	Scope	' 4'	' 29'	We think that this needs to review what models already exist to avoid reinventing the wheel. It also needs to be fully multidisciplinary including therapists, not just a medical model. What are the gaps in provision of rehab?
233	Royal College of Speech and Language Therapists (RCSLT)	Scope	' 4'	' 32'	In 'access to services' , please ensure speech and language therapy is on the list. We also suggest asking patients for their views on the use of digital information, rehab platforms and telehealth.
234	Royal College of Speech and Language Therapists (RCSLT)	EIA	'3 '	'General comment Socio-Economic'	Consider specific mention of Speech, Language and Communication Needs (SLCN) across life span and the impact of this on accessing information in any modality. Low levels of literacy and higher prevalence of pervasive language disorder are known to exist in these communities already identified to be at higher risk for COVID. In addition for BAME populations, barriers to access include low levels or no spoken English, resulting in

ID	Stakeholder	Document	Page no.	Line no.	Comments
					the need for an interpreter.
235	Royal College of Speech and Language Therapists (RCSLT)	Scope	'4'	'29'	This should take into account the wider learning internationally, about creating the conditions for integration and integrated person-centred care. It should also specifically mention health, social, third sector and voluntary roles and community-based assets for a holistic, person centred approach.
236	Royal College of Speech and Language Therapists (RCSLT)	Scope	'Page 2'	'Line 3'	'…are not explained by an alternative diagnosis' could this sentence be changed to: 'New symptoms consistent with SARS-CoV-2 3 virus that develop and continue for more than 12 weeks post infection'
237	Royal College of Speech and Language Therapists (RCSLT)	scope	'Page 3'	'Line 13'	It may also be of value to health care providers outside of the UK, and researchers (as per comment 2).
238	Royal College of Speech and Language Therapists (RCSLT)	scope	'Page 4'	'Line 31'	These questions are service provider focused and may therefore miss some subtleties about lived experience. Is there an opportunity to create focus groups and define the question agenda/themes via information which emerges rather than pre-defined concepts?
239	Royal College of Speech and Language Therapists (RCSLT)	scope	'Page 6'	'table'	As the NICE QS158 &CG83 Rehabilitation after critical illness in adults is referenced – it's not clear why the post- intensive care syndrome (PICS) cohort would be excluded, as there isn't a clear point in time where PICS stops and chronic issues start, it's a rehab continuum, so would be useful to include this group of patients.
240	Royal College of Speech and Language Therapists (RCSLT)	EIA	'Page 2'	''disability''	We suggest adding: 'People with communication compromise may not be able to describe, explain or communicate subtle or complex symptoms which may not be obvious to those caring for them. These specific and unique issues have the potential to impact on health care accessibility'

ID	Stakeholder	Document	Page no.	Line no.	Comments
241	Royal College of Speech and Language Therapists (RCSLT)	EIA	'Page 3'	'Socioeconomic factors'	Poverty may also impact on the individual's ability to access online materials/apps for GP appointments and health information, creating a further barrier within a health literacy and access context.
242	Royal College of Speech and Language Therapists (RCSLT)	Scope	'Page 2'	'line 5'	Post-COVID syndrome has been described by some sufferers as a relapsing-remitting process (including within the NIHR qualitative research project on long COVID) it would therefore be helpful to capture this in the definition and description.
243	Royal College of Speech and Language Therapists (RCSLT)	Scope	'Page 4'	'Lived experience '	These questions are likely to miss something if they are not defined by patients themselves and aligns with our earlier comment about person centred care. Judicial use of the NIHR Long COVID report details should help this; even with the rapid timelines, access to a patient advisory group or patient partner as part of the guideline development would help to balance this.
244	Royal College of Speech and Language Therapists (RCSLT)	Scope	'Page 6'	'Related NICE guidance'	This is another key guideline that needs to be linked to and signposted: Workplace health: long-term sickness absence and capability to work NICE guideline [NG146]
245	Royal College of Speech and Language Therapists (RCSLT)	Scope	'Page 5'	'Exclusions'	As per an earlier comment, exclusion of Post ICU syndrome is not consistent with the scope or other documentation of Long COVID. An additional aspect is that from clinical experience patients who have had COVID and been admitted to ICU have psychological challenges that relate specifically to their diagnosis — comparative to other PICS survivors (e.g. stigma and isolation). These may be better managed within services specific to COVID.
246	Royal College of Speech and Language	EIA	'Page 3'	'Sex'	There is emerging evidence that long COVID (in those who do not require hospital care) may be more prevalent in women: https://institute.global/policy/long-covid-reviewing-science-and-assessing-risk

ID	Stakeholder	Document	Page no.	Line no.	Comments
	Therapists (RCSLT)				This may also need to be acknowledged in the document as more data becomes available.
247	Royal College of Speech and Language Therapists (RCSLT)	EIA	'Page 4'	'Digital accessibility '	Lack of access to online resources due to digital poverty should be included.
248	Professional Advisory Group – Clinical Guidance Cell, Scottish Government	scope	''	'19 -21'	I wonder why there is an assumption that specialist care will be delivered by secondary care rather than by primary care or by health and social care partnerships?
249	Professional Advisory Group – Clinical Guidance Cell, Scottish Government	scope	''	'19-21 '	In addition, should there be some consideration given to What symptoms or signs would indicate that access to self management resources would be beneficial?
250	Professional Advisory Group – Clinical Guidance Cell, Scottish Government	scope	''	'26'	By monitoring are you referring to and/or including outcome measures?
251	Professional Advisory Group –	scope	''	'26'	Are you including self assessment under monitoring?

ID	Stakeholder	Document	Page no.	Line no.	Comments
	Clinical Guidance Cell, Scottish Government				
252	Professional Advisory Group – Clinical Guidance Cell, Scottish Government	scope	"	'29'	Need to consider the range of rehabilitation interventions from informal and self directed care to specialised rehabilitation (Ref WHO rehabilitation in Health Framework)
253	Professional Advisory Group – Clinical Guidance Cell, Scottish Government	scope	"	'23'	Does there need to be a specific question about the evidence for and use of digital technology or are you confident this is captured in this question?
254	Professional Advisory Group – Clinical Guidance Cell, Scottish Government		"	'32 &19'	You are asking peoples experience of access to services. I wonder if we need to look at what the evidence says about access. I wonder if the referral section could also consider access?
255	Professional Advisory Group – Clinical Guidance Cell, Scottish	scope	'2'	'6&7'	Long term conditions primary and secondary prevention are a huge workload in general practice and indeed will long Covid patients become part of that LTCs family? What guidance will there be regarding review and treatments across both primary and acute services? Will different specialities be involved?

ID	Stakeholder	Document	Page no.	Line no.	Comments
	Government				
256	Professional Advisory Group – Clinical Guidance Cell, Scottish Government	scope	'4'	'22'	Management of symptoms. Again I suspect the work load to fall in primary and community care and the teams within them, so resources staffing as well as pharmaceutical treatments will need considered.
257	SIGN Council	EIA	'General'	'General'	Would be useful to see some kind of intersectional analysis (where the outcomes for those with more than one protected characteristic are particularly concerning e.g. older BAME men who experience socio-economic deprivation)
258	SIGN Council	Scope	'General'	'General'	I feel the guideline scope would benefit from looking at the impact on the quality of life for patients with pain\fatigue\restriction on daily activities, education, working and social life and the impact on the family. QOL questionnaires may be identified as effective measurement tools for patients to monitor change in QOL over time.
259	SIGN Council	Scope	'General'	'General'	What is the patient's experience of access to information about COVID-19 and self management? Are there any tools available to aid patient shared decision making in relation to COVID-19?
260	SIGN Council	Scope	'General'	'General'	I wonder if medicines in the pipeline/clinical trials should be identified and updated as evidence is published. It might also be worth identifying what pharmacological interventions have proven not effective for the treatment of COVID-19 symptoms.
261	SIGN Council	Scope	'1 and 2'	'Case definition'	If -ve COVID PCR and -ve antibody test – does this exclude long COVID (suggest it should) e.g. how would CFS be differentiated from post COVID (see P5 ln10/11) ?
262	SIGN Council	Scope	'4'	'9'	Define risk factors (eg genetic, co-morbidities, sociodemographic etc)
263	SIGN Council	Scope	'General'	'General'	The questions are good, but evidence is likely to be very limited due to timelines of where we are in the pandemic. How will evidence from other chronic disease conditions be considered, as there this may be useful in directing care: eg post ICU syndrome, and CFS are excluded, but there may be evidence from management of this that could inform a stepped model of care.
264	SIGN Council	Scope	'4'	'31'	Presumably there will be input to the rest of the guideline from PWLE
265	SIGN Council	Scope	'General'	'General'	We believe there is a gap in the proposal to more comprehensively consider the mental health impacts of COVID-19 in the management of Post-COVID-19 syndrome.

ID	Stakeholder	Document	Page no.	Line no.	Comments
					Research shows that there is often an increased risk of co-morbid mental health problems developing alongside a long-term or ongoing physical illness and this is very likely to be the case in relation to post-COVID 19 syndrome as well. Therefore, we would like to see an expansion of the proposal to more comprehensively factor in psychological impacts of post-COVID 19 syndrome and for there to be a full choice of evidence based psychological therapies made available for all people with identified as having post-COVID 19 syndrome. The importance of choice when make psychological therapies available is well established within research literature, with a clear link between co-design and joint decision making around intervention options and improved outcomes for the individual. If you have any questions about our comments please do let me know and we will strive to provide more information.
266	SIGN Council	Scope	'4'	'30'	What components should be included in a service model for the delivery of services to people with post-COVID-19 syndrome? This implies that there is one service delivery model. This is perhaps suitable where there are to be COVID-19 clinics, but does not reflect the approach in place in NHS Scotland It would be better phrased as: “What components should be included in models of service delivery to people with post-COVID-19 syndrome?”
267	SIGN Council	Scope	'2'	''	Post-COVID-19 syndrome. I am content with this terminology but it might be important to ensure that patients and their families recognise that this means after the acute phase, rather than after COVID-19.
268	SIGN Council	Sope	4	15 and 25	Need to add school due to CYP being in the scope.
269	SIGN Council	Sope	4	15 and 25	Need to add school due to CYP being in the scope.
270	The Renal Association		'General'	'General '	I have also read the documents and don’t think there is anything to add from the Renal Association point of view.
271	The Richmond	Scope	'2'	'2'	We support the distinctions between ongoing symptomatic covid and long covid. This will help patients to

ID	Stakeholder	Document	Page no.	Line no.	Comments
	Group of Charities				understand the progress of their symptoms and know at what stage they are able to access more intensive support. We strongly agree that there should be the possibility of a long covid diagnosis before 12 weeks, where appropriate, and look forward to seeing more information on how the diagnosis can be made early.
272	The Richmond Group of Charities	Scope	'3'	'8-13'	The 'Who the guideline is for' section should be expanded to include organisations who provide accessible information to patients; including charities and the professional bodies.
273	The Richmond Group of Charities	Scope	'4'	'22-30'	The key questions: 'Management and rehabilitation' section should include specific consideration of the risks and benefits of the use of corticosteroid injections in people with ongoing symptomatic COVID-19.
274	The Richmond Group of Charities	Scope	'4'	'31'	It is welcome that the impact of covid on BAME groups is referenced in the EIA. We would urge NICE to prioritise recruiting and consulting with people with lived experience of long covid from BAME groups as part of this work.
275	The Richmond Group of Charities	Scope	'4-5'	'4/31-5/4'	The key questions: 'Lived experience of people' theme should be expanded to include the experience of families and carers.
276	The Richmond Group of Charities	Scope	'4'	'31'	Asthma UK and the British Lung Foundation set up a post covid hub during the first wave of the pandemic in response to the growing awareness that people who caught covid were at risk of ongoing respiratory problems. Through this they are running a rolling survey to gather insight and would be delighted to work with NICE to share this and help recruit people with lived experience to contribute to the development of the guideline https://www.post-covid.org.uk/
277	The Richmond Group of Charities	Scope	'4'	'31'	We believe it would be helpful to also ask people with lived experience of long covid to feed back on their experience so far of HCP understanding and willingness to support them. AUK-BLF insight work is showing that people with long covid symptoms are often dismissed by HCPs or assumed to be suffering from anxiety, or their HCPs simply do not know what support to offer them.
278	The Richmond Group of Charities	Scope	'6'	'1'	There is evidence that some people who have experienced severe covid may develop fibrosis of the lungs. We understand that this is out of scope given that there is existing guidance to deal with this, it may be helpful to reference this in table 2 https://www.nice.org.uk/guidance/conditions-and-diseases/respiratory-conditions/pulmonary-fibrosis.
279	The Royal College of	EIA	'2'	'General'	We are pleased that pregnancy and maternity are specifically mentioned in this document

ID	Stakeholder	Document	Page no.	Line no.	Comments
	Obstetricians and Gynaecologists				
280	The Royal College of Obstetricians and Gynaecologists	Scope	'General'	'General'	The term 'Long COVID' is being increasingly used (including on the names of the consultation documents). It might be worth acknowledging this in the introduction of the scope.
281	The Royal College of Obstetricians and Gynaecologists	Scope	'1'	'23 & 25'	It would be clearer to say that the acute infection causes symptoms in the first 4 weeks and ongoing symptomatic COVID-19 from 4 to 12 weeks
282	The Royal College of Obstetricians and Gynaecologists	Scope	'2'	'6 & 7'	There is emerging evidence that COVID-19 has a prolonged course during pregnancy and the postnatal period; these women may need special consideration in the guideline (Afshar et al 2020)