Summary of consultation comments and responses for COVID-19 guideline scope: management of the long-term effects of COVID-19

A targeted consultation on the draft scope for the guideline on the management of the long-term effects of COVID-19 was conducted from 23rd to 27th October 2020. A total of 66 consultees from 48 organisations were contacted, including patient involvement groups, the Royal Colleges and medical professional societies and provider and academic organisations. A total of 283 responses were received representing a broad range of expertise.

This document provides a thematic summary of comments and responses. All consultation comments are provided in full on the NICE webpage.

Scope area	Key comments	Response
1 Clinical case definition and rationale	**Acute COVID-19 definition** • Some responses expressed concerns over the draft clinical case definition not being precise enough, as it does not limit to previous confirmed infection (microbiologically or clinically probable/possible). It was suggested this could potentially miss the opportunity to target services to those who will benefit the most. • Comments stated that as diagnosis includes those who self-report symptoms there could be cross-over with people who developed ME/CFS symptoms early in the pandemic, which may be then conflict with the exclusion criteria	The panel concluded that many people (especially at the start of the pandemic) would not have had a test for COVID-19 and therefore people who were diagnosed on the basis of clinical signs and symptoms should also be included. The definition was not changed to be made more precise as limiting to previous confirmed infection could exclude a people who had post-COVID-19 syndrome. The panel acknowledged that there are many different symptoms relating to post-COVID-19 syndrome and there is likely to be overlap between the symptoms of other illnesses with post-COVID-19 syndrome. One of the key questions in the scope for this guideline is to address the prevalence of symptoms or clusters of symptoms in people with ongoing

		symptomatic COVID-19 and post-COVID-19 syndrome in order to try and address the cross-over. Please note that the management of ME/ CFS is excluded from this guideline.
	Ongoing symptomatic COVID-19 definition • Comments expressed some confusion in the '3-4 weeks' description used for the ongoing symptoms section. 4 weeks was the most favoured timepoint.	The panel concluded that ongoing symptomatic COVID-19 should be described as starting at 4 weeks after initial acute COVID-19 infection.
	Post COVID-19 Syndrome definition • Responses suggested misunderstanding of the use of '12 weeks' as denoting the end point of Post Covid-19 Syndrome rather than the start.	No change was made to the definition. The panel discussed the definition and confirmed that post-COVID-19 syndrome can extend beyond 12 weeks after the initial acute COVID-19 infection.
	• Comments highlighted that the case definition seemed to limit Post Covid-19 syndrome to "new symptoms" (page 2 line 1) but argued that symptoms may or may not be new.	The panel agreed that symptoms associated with post COVID-19 syndrome were not necessarily new at 12 weeks after initial infection, but could have developed in the initial acute infection phase and continued.
	• There was disagreement on the use of "post" in the case definition. This is because it may not be clear when or if the acute phase has resolved but "post" implies initial symptoms have resolved or there are new symptoms with a different origin. Some comments suggested the use of 'chronic COVID infection'	The panel discussed this and agreed not to change the wording of the case definition. The panel agreed that the rationale for the use of the word 'post' needed clarifying and amended this to make it clearer. The panel did not agree with using the term chronic as this implies ongoing infectivity and the evidence base is not mature enough to label the symptoms of post-COVID-19 syndrome as chronic.
	Some comments indicated that the term "acute illness" caused confusions. Some interpreted this as the scope defining the acute stage as the most severe part of the illness which they disagreed with.	No change was made. The panel agreed that acute referred to the initial infection.

	• Responses voiced concerns that Post-Covid-19 syndrome is difficult to distinguish as an isolated syndrome. One response referred to the NIHR report that considers 3 conditions that may be presenting.	The panel acknowledged that there is a lot of uncertainty around post-COVID-19 syndrome. However, they agreed that a term was required in order to recognise this as a diagnosis and ensure people receive appropriate care. This guideline and the case definition within it are subject to a 'living' approach: as and when more information is available the definition can be updated to reflect this.
	• It was commented that one symptom plus no need for previous confirmed COVID-19 might be overinclusive and lead to significant cross-over with other post-viral syndromes. There was also a suggestion from one patient group that the majority of people have many symptoms and that one symptom is inaccurate.	The wording has been clarified to say '1 or more'.
	• Some strong disagreement from one respondent on the linear approach to the definition which 'ignores' the relapsing-remitting nature of the condition. The response stated that the scope was in danger of "oversimplifying a complex illness" that "imposes a pattern" that may "marginalise" those who do not fit this pattern and increase stigma. This is somewhat supported by other comments which suggest "fluctuating acuity" and "higher acuity some weeks after infection".	The rationale for the case definition has been updated to reflect that symptoms can fluctuate.
	• There seems to be some confusion over the two phases (ongoing and post-COVID). Some comments suggested that the intermediate step might not be necessary although other responses accepted the intermediate step to try and distinguish between the acute condition and	The panel acknowledged the issues raised, but concluded that for the purposes of this guideline the use and definition of different stages: acute COVID-19 infection, ongoing symptomatic COVID and post-COVID-19 syndrome were appropriate and as stated would be subject to ongoing and

	ongoing symptoms. One stakeholder suggested dropping the phase names and using symptom duration to define the phases (e.g short, medium and long duration).	continuous review as part of a ‘living’ proactive approach to the development of guidance.
	Use of Post COVID-19 syndrome as the name • Responses highlighted that ‘Long COVID’ is a patient embraced term. • One respondent strongly disagreed with the suggested term ‘post-COVID’ and argued that ‘Long COVID’ better captures patient experience compared to “post-COVID-19" due to the ongoing nature of the condition. • One respondent highlighted that the term ‘post COVID-19' fits better with the NHSE Framework for Long Term Conditions	The panel discussed various options for naming the condition, but concluded that ‘post-Covid’ was appropriate for the purposes of this guideline. The panel recognised that ‘Long COVID’ is a patient embraced term and has many benefits. However, they balanced this against the need for a formal recognition of the condition in the medical setting and to implement appropriate services and coding to support the care of people with post-COVID syndrome.
	Exclusions • There was disagreement from one respondent about excluding Post Intensive Care Syndrome as they feel this cannot be reliably separated from Post COVID Syndrome.	The exclusions section has been amended to make it clearer that these are exclusions to inform the evidence search. The wording has been amended to reflect that this section of the scope defines what will not be searched for in the evidence, for example the management of post intensive care syndrome.
	Other considerations • Respondents suggested adding “endocrine” and “immunological” to the list of signs and symptoms (page 2, lines 23-28 of scope).	These were not added because this is not an exhaustive list.
	• Responses suggested that the scope does not make it clear that we are looking at people from any setting.	People in all settings are included in the scope of this guideline.

2 Who the guideline will cover	From 'general' comments: • It was suggested that there is difficulty in using syndrome to exclude groups by cause • Comments were received requesting a clear definition of 'young people' and proposing separate statements for long-COVID in children (aged <18). • Responses included comments on the appropriate duration of the acute phase, with some stakeholders asserting that it should be more specific and set at 4 weeks. There was a suggestion that line 4-5 of draft should be "COVID-19 symptoms" and not "COVID-19 infection". • The current scope does not seem to cover patients who develop long-COVID after few symptoms and/or no antigen test.	The panel concluded that for the purposes of this guideline the term 'syndrome' is the most appropriate to use, no change was made. No change was made, this is standard wording where the scope of a guideline includes people under 18 years of age. The guidance may contain separate recommendations for children and young people if appropriate. Duration of illness was amended to 4 weeks after initial COVID-19 infection to align with the amended case definition. This group of people are included in the scope of the guideline, it was concluded that no change was needed to the wording in the scope.
3 Who the guideline is for	From 'general' comments: It was suggested that the guideline may also be of use to: • Local authorities and social care providers who may need to support people with post-COVID 19 in the community	It was agreed that the guideline may be used by these groups, but these were not added to the section on 'who the guideline is for' because this section relates to who the guidance is commissioned for, and the wording is standard to denote the primary audiences.

	- Employers to understand that employees with post-COVID 19 have long-term legitimate illnesses - Respondents suggested that this section should include parents for children under 18, carers/guardians and family members Multiple suggestions for additional groups to include in this section were received: - Researchers - Policy makers - Employers, independent, third sector and voluntary providers of social support - Primary healthcare practitioners, including occupational health - Patient charities and professional bodies - Paediatric specialists	
4 Equality considerations	From 'general' comments: - Scope overlooks key influence of mental illness as a comorbid condition and on health inequalities in this group. Equalities Impact Assessment comments - age - Suggestion to remove living alone' from paragraph 2 as living with someone else doesn't ensure ease of access - It was pointed out that some existing services have age referral / exclusion criteria which may lead to inequitable access - One comment suggested that it may be useful to have mention of adults or younger adults as	The panel discussed the importance of mental health for this topic and made a number of amendments to make it clearer that this influence and the importance of consideration of mental health was acknowledged. All comments about the equalities impact assessment (EIA) were discussed by the panel and added into the EIA.

	well as children, younger people and those over 65 - One comment requested clarification of evidence on higher rates of reporting of prolonged COVID in older groups - Query around potential limited access to technology for older people causing issues, for example accessing and reporting symptoms on Apps - Mention around older adults with acquired communication impairments or dementia – needs to be highlighted as a vulnerable group Equalities Impact Assessment - disabilities - Two comments suggested highlighting that COVID-19 symptoms may result in disability and create challenges with seeking and accessing help / services Equalities Impact Assessment - race - One comment highlighted a recent report suggesting that there is increased risk in the BAME community related to comorbidities, obesity, and social and work environments. - Another commented that it is important to highlight the potential impact of racism on interactions with the healthcare system, 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 Equalities Impact Assessment - sex	

	• Query about where the evidence that more women are affected than men by Long COVID is derived from. Another comment suggested that this is supported by emerging evidence Equalities Impact Assessment - socioeconomic factors • Access to computers and literacy issues which are greater among those most disadvantaged not mentioned • One suggestion to mention the inability to buy OTC treatment to help symptoms • Another comment suggests that this section needs to be strengthened as social deprivation has a much larger impact on health outcomes than merely “accessibility to health care resources”. One comment flagged emerging evidence of a link between social deprivation and incidences of COVID-19 that needs to be explored more fully. Equalities Impact Assessment - other definable characteristics • Comments highlighting that prisoners and gypsy/traveller communities seem to be excluded. Also armed forces personnel and those who have been trafficked. Equalities Impact Assessment section 1.3 • Comment requested guidelines 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. Communication • One comment argued that communication needs across the lifespan needs to be highlighted – people may not be able to communicate, describe or explain subtle or complex symptoms. Need to highlight speech, language and communication needs • Low levels of literacy and pervasive language disorders are known to exist in communities at higher risk of COVID-19 and some language limitations in some BAME populations Mental Health / pre-existing co-morbidities • 2 suggestions to include mental health or pre-existing co-morbidities which may create challenges for seeking help and accessing services Care homes • One comment suggested 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.	

5 Proposed themes and questions	From ‘general’ comments: • Respondent proposed new theme of ‘Research priorities’ • Suggestion to potentially include recs on implementation and resources, given NHS pressures: patient and regulatory expectations, NHS staffing, equipment	No new themes were added. The panel discussed that research recommendations could be made in the guideline if required. No change was made to the scope as this will be discussed during development.

	Proposed additional key questions from respondents • What assessments should be carried out to identify individual need and determine appropriate management and rehabilitation requirements? • 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? • Consideration of a key question around use of telemedicine during the pandemic. **Replacement of current key questions** One respondent proposed to replace key question on ***referral to specialist care*** with three new questions • What models of care and 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? • How are services accessed in a timely way and in response to individual need? One respondent proposed to replace first two questions under ***management and rehabilitation*** :	The panel acknowledged the helpful suggestions, but concluded that in the main these questions were covered by existing review questions. They amended the question of patient experience to ask 'What are the views and experiences of patients, their families and carers…' It was noted that the use of telemedicine will be covered by the question on elements of service delivery. The panel acknowledged the helpful suggestion, but it was concluded that the existing review question was sufficient and no change was made to these key questions.

	- 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? - What monitoring is helpful to assess deterioration, fluctuation or recovery, and the ongoing appropriateness of the referral pathway?	The panel acknowledged the helpful suggestion, but it was concluded that the existing review question was appropriate and no change was made to these key questions.
	Theme: Investigation and assessment **Key question 1** - Responses asked if this question should define risk factors of interest, for example pre-existing physical and mental health problems, genetics, comorbidities, sociodemographics, etc.	No change was made as this level of detail will be in review questions.
	Key question 2 - Responses asked if the question should state a duration of 4 to 12 weeks rather than 3 to 12?	This has been amended to 4 to 12 weeks
	- One response highlighted that It is often not possible to distinguish between physical and psychological symptoms. - A respondent suggested - What is the prevalence of long-COVID in hospitalised versus self-managing patients in the community?	It was concluded that this detail was covered by the broader review questions.
	Key question 3	

	• Response suggested adding impact on relationships, caring responsibilities and ability to participate in education.	Education was added to this list, but please note these are not a definitive list.
	Key question 4	
	• Response suggested replacing “should” with “could” due to emerging nature of the evidence base.	No change made.
	• Response suggested separating out primary and secondary care pathway for investigations in this question.	It was concluded that this level of detail will emerge from the review questions.
	Key questions 1-4	
	• Respondent asked - “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?”	It was concluded that this level of detail was not needed in the scope.
	• Respondent asked - “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?”	It was concluded that this level of detail was not needed in the scope.
	Other comments	
	• Respondent suggested - What screening tools, frameworks and guidelines already exist to assess symptoms and functional impairments?	It was concluded that this level of detail was not needed in the scope.
	Theme: Referral to specialist care **Key question 5**	

	- Respondent suggested expanding secondary care to incorporate psychology, rehabilitation medicine and physiotherapy interventions.	The term ‘secondary care’ has been replaced with ‘specialist care’ to reflect these specialities.
	Management and rehabilitation **Key question 3 and 6** - Respondent suggested adding school/education due to children and young people being in the scope.	Education was added to ‘usual activities’ where relevant to capture the experiences of children and young people
	Key question 8 - Respondent suggested consideration of whether the key question should review existing models to avoid reinventing the wheel.	It was concluded that this level of detail was not needed in the scope.
	- Respondent suggested the question should reflect the holistic, person-centred model of patient care.	It was concluded that this level of detail was not needed in the scope.
	- One responder queried whether a single service model is feasible or desirable for a complex syndrome. A more relevant question is what existing services need to work together to provide care for this patient group.	It was concluded that the current questions covered the issue of services working together.
	Other comments - One responder expressed concern there was no key question around management of relapsing-remitting long-COVID cases.	The definition of post-COVID-19 syndrome was amended to take into account the fluctuating nature of the illness.
	- Responder suggested - What early interventions could prevent the development of post-COVID-19 syndrome or potentially decrease the period of ill-health?	

	Theme: Lived experience **Key question 9** • Suggested addition by a responder of an additional bullet point: “the needs of families and carers” by two responders. • Comment proposed inclusion of patient views on use of telemedicine. • Respondent suggested that themes in this section should be defined by patients or emerge from the evidence rather than being prespecified. **Themes (general)** • Respondent suggested adding 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). • Respondent suggested inclusion of barriers to presenting/patient awareness of symptoms.	It was concluded that prevention was not within scope of this guideline. Question amended to take into account views of patients, families and carers. Telemedicine not added as this is already covered by existing questions. Question added on patient views of signs and symptoms of post-COVID-19 syndrome and information and support provided. It was concluded that the existing review questions covered these issues.

Themes to be excluded	Several responders queried the exclusion of people with conditions that have symptoms similar to long-COVID, e.g. ME/CFS or post-ICU syndrome as follows: • Difficulty in distinguishing between post-COVID syndrome and CFS, ME, fibromyalgia, etc. • Should patients with organ damage or ME/CFS which are often symptomatic of long-COVID be excluded from the guideline? • There may also be increased risk of long-COVID in patients with pre-existing CFS/ME, etc. • How will overlapping symptoms & experiences be attributed to one or the other?	The section on themes to be excluded has been changed to ‘themes to be excluded from the evidence search’ and the detail within this section has been amended to reflect that the management of these conditions where there are already defined pathways of care are excluded from the search for evidence, in order to focus on post-COVID syndrome and avoid overlap with other care pathways and existing guidance.
	Respondent 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”	The wording was amended to make it clearer what was intended by the themes to be excluded.
	Respondent stated that it should be less than 4 weeks symptoms for acute COVID.	Acute COVID-19 was amended to less than 4 weeks.
6 Related NICE guidance	Suggested additions: • NICE guidelines for pulmonary rehabilitation - are aimed primarily at COPD and asthma but do have an evidence base. • NICE guidelines for FM - they are useful in what is unlikely to work but also covers many of the symptoms.	No changes have been made to this section as this is guidance that is directly related to the management of the long-term effects of COVID-19. If, during the development of the guideline, relevant recommendations on the areas highlighted are identified, these will be cross referenced appropriately in the guideline.

	- NICE guidelines for pulmonary rehabilitation – they are aimed primarily at COPD and asthma but do have an evidence base. - Workplace health: long-term sickness absence and capability to work NICE guideline [NG146]	
	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.	No action needed.
	One respondent stated that 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.	Please see 'themes to be excluded' section responses
7 About COVID-19 rapid guidelines	No comments received	No action needed.
General comments	**Naming** - It was argued that the scope should acknowledge term 'Long Covid' in the introduction - Respondents expressed concern that 'post' implies disease process has finished – it was suggested that other terms may better fit with 'living approach' to guideline **Psychiatric aspects**	Scope amended to acknowledge. The expert panel discussed this issue and concluded that the rationale provided for use of term 'post-COVID-19 syndrome' was appropriate and that this was suited to a 'living' approach.

	- It was argued that explicit consideration should be given to cognitive problems/impairments, and role of psychometric assessment - It was argued that explicit consideration should be given to psychiatric symptoms, and role of psychiatry, including investigative tools, psychopharmacological treatment, and links between psychiatric disorders and 'long Covid' - Respondent asked for acknowledgement of wider mental health and suggested signposting to important literature, including on MERS - Stakeholder suggested a psychiatrist be included in guideline development	Panel agreed that s should be explicit in the scope. The panel added 'mental health' to key questions to ensure both physical and psychiatric/ psychological symptoms considered. There is representation from a psychiatrist on the panel.
	Impact on quality of life - Respondent asked that quality of life aspects are explicit in scope	It was concluded that this level of detail was not needed.
	Patient experience - Respondent Requested inclusion of patient experience of access to information on COVID-19; self-management and - patients' views on advice and guidance available/provided	No action required, this will be included in review questions. Amended question 9 on patient experience to include patient views on information and support provided.
	Medicines - Respondent request to include mention of medicines in development/being trialled, and update as evidence becomes available. Include	It was concluded that this level of detail was not needed in the scope. The review questions on interventions include pharmacological and the development and updating of this

	mention of ineffective medicines for treating symptoms. **Evidence from other conditions** - Respondent flagged evidence from other conditions – see also psychiatric aspects above – which could help inform stepped model of care	guideline will be through a 'living' approach, with surveillance of evidence and updating being continuous and proactive. No action needed.