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

A targeted consultation on the draft guideline on the management of the long-term effects of COVID-19 was conducted from 13th September 2021 to 27th September 2021. A total of 46 consultees commented, including patient involvement groups, the Royal Colleges and medical professional societies and provider and academic organisations. A total of 520 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.

Please note that some of the recommendation numbers referred to in comments relate to the previous consultation version of the guideline.

Scope area	Key comments	Panel considerations and responses
Case definition	**Acute COVID-19** Signs and symptoms of COVID-19 for up to 4 weeks. **Ongoing symptomatic COVID-19** Signs and symptoms of COVID-19 from 4 weeks up to 12 weeks. **Post-COVID-19 syndrome** Signs and symptoms that develop during or after an infection consistent with COVID-19, continue for more than 12 weeks and are not explained by an alternative diagnosis. It usually presents with clusters of symptoms, often overlapping, which can fluctuate and change over time and can affect any system in the body. Post-COVID-19 syndrome may be considered before 12 weeks while the possibility of an alternative underlying disease is also being assessed.	

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	In addition to the clinical case definitions, the term ‘long COVID’ is commonly used to describe signs and symptoms that continue or develop after acute COVID-19. It includes both ongoing symptomatic COVID-19 (from 4 to 12 weeks) and post-COVID-19 syndrome (12 weeks or more).	
	***[based on 21 comments*]**	
	Differentiation of timescales There was a positive comment from 1 stakeholder who said the “The differentiation of timescales to acute, ongoing or extended and chronic illness is a valuable distinction”. However, another stakeholder mentioned that having separate terms “may be unhelpful for clinicians as evidenced by the use of the coding for “ongoing symptomatic COVID-19” which has not been widely used within primary care. (Clinical coding of COVID in English Primary Care BJGP August 2021)” and suggest having one clinical definition (12 weeks Post COVID-19 syndrome) but make it clear that this should not be used as the time scale for referrals and investigations which should remain at 4 weeks and onwards. Another stakeholder raised concerns that having the timeframes in the definition would “pose the risk of being not getting taken seriously if they don’t meet arbitrary criteria”. One stakeholder suggests that it is “important to acknowledge that to date there is insufficient evidence to assume that Long Covid is a continuation of an acute Covid-19 illness during the ‘ongoing symptomatic stage’ or that this stage stops at a definitive time (12 weeks)” and that it is important that patients may be experiencing the same symptom course even at the different time points.	As stated in the rationale, specific clinical diagnostic criteria were needed to facilitate access to support, provide the basis for planning services and to enable formal codes to be developed for clinical datasets. Whilst the evidence shows that the coding is currently not being utilised as this case definition indicates, there are several possible causes of this aside from the separate timepoints in the definition. The case definition will be reviewed using a ‘living’ approach and may be modified as more data on clinical coding emerges. The panel noted that this data was collated soon after the coding was made available. Whilst the definition uses timepoints to distinguish between ongoing symptomatic COVID-19 and post-COVID-19 syndrome, it is not the intention of the panel to base recommendations for advice, referrals, investigations or management exclusively at these timepoints. The recommendations under the identification section encourage providing information on common symptoms, expected recovery time, self-management and who to contact if someone is worried about new, ongoing or worsening

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		symptoms. There are also considerations for urgent referral where required regardless of when an individual presents with the symptoms.
	Use of 'post-COVID-19 syndrome' as the condition name One stakeholder raised concerns that 'post COVID-19 syndrome' has "inaccuracies and stigmas" that implies that the condition is "merely a viral illness that clears up of its own accord" and is "concerned the panel continue not to listen to patients". One stakeholder suggested that 'Long COVID' is still the preferred term for patients and another stakeholder suggested other colloquial terms to be added to the definition e.g. 'long haul', 'long tail'.	The rationale for using "post COVID-19 syndrome" is explained in the scope: Post: Signs and symptoms that continue after the acute phase of COVID-19. This does not assume that the COVID-19 illness is over or that people have recovered, but the acute phase has usually ended Syndrome: Signs or symptoms that exist together. People may have 1 or more ongoing symptoms and still be included in the definition. The guideline recognises the use of 'long COVID' in addition to the clinical case definitions.
	More granular definition needed One stakeholder recognises the rationale for not updating the case definition but feel that this will be disappointing to many. They favour a more granular definition that "would help improve the quality and comparability of research undertaken, as well as potentially enable an increased focus on available treatments. The existing definitions are broad and do not support distinguishing between those with severe symptoms and those who are less significantly impacted". They query whether the scope of the definition could be developed outside of the formal guideline process.	Based on the evidence reviewed, it was decided not to update the case definition at this time. Whilst there is some emerging evidence on suggesting different phenotypes or clusters of symptoms experience by people, the panel decided the evidence base is still not strong enough to make the case definition more granular. However, the case definition will be reviewed as part of a 'living' approach and can be modified as new evidence emerges.

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	Another stakeholder suggested that “there is no sub classification within the very wide definition, hence interpretability and analysis is going to be incredibly difficult.”	
	Mandatory proof of infection One stakeholder was concerned that the lack of mandatory proof of infection within the case definition creates “noise” in the system and “anxiety for all those who self-identify with long COVID”	The panel did not want to include mandatory proof of infection as a criterion for diagnosing those experiencing the long-term effects of COVID-19. This is because testing was not readily available at the beginning of the pandemic and antibody serology testing may not be a reliable indicator of previous infection. Therefore, introducing this criterion would exclude a large proportion of people who identify as having long COVID from the guideline. This approach will be reviewed at a future timepoint as it is acknowledged that testing for symptomatic and asymptomatic people is now more readily available.
	Diagnosis of exclusion One stakeholder raised concerns about post-COVID-19 syndrome being a diagnosis of exclusion. They would favour it to be “keep as an umbrella term to enable equitable access to services, and to then be considered alongside alternative diagnoses”. They have concerns that there is a “risk that once one condition has been confirmed that all symptoms are put down to that and not adequately assessed”. Another stakeholder needed clarity on whether post-intensive care syndrome (PICS) would be included in potential alternative diagnoses as would have a large overlap in terms of symptoms of post-covid-19 syndrome. They have concerns that “Including PICS as an “alternative diagnosis” in the definition of ‘post-COVID-19 syndrome’, thereby	The panel acknowledged that this case definition may be interpreted as a diagnosis of exclusion. However, they discussed that ongoing symptomatic COVID-19 and post-COVID-19 syndrome have many features in common with other conditions including post-intensive care syndrome. Some of these features could be considered life threatening. Therefore, ongoing symptomatic COVID-19 and post-COVID-19 syndrome should not be the first conditions to be excluded for reasons of patient safety. The benefits and harms section of the evidence to decision for case definition in the guideline has been updated to reflect this.

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	excluding patients recovering after a critical illness from being diagnosed with 'post-COVID-19 syndrome', would be undesirable, as it could potentially exclude these patients from the measures described in this NICE guidance".	
	WHO definition Comments from 2 stakeholders suggested aligning our case definition with the WHO definition of "Post COVID-19 Condition" which has a single definition. [WHO definition: A clinical case definition of post COVID-19 condition by a Delphi consensus, 6 October 2021 (who.int) Post COVID-19 condition occurs in individuals with a history of probable or confirmed SARS CoV-2 infection, usually occurring 3 months from the onset of COVID-19 with symptoms and lasting for at least 2 months, that cannot be explained by an alternative diagnosis. Common symptoms include fatigue, shortness of breath, cognitive dysfunction but also others and generally have an impact on everyday functioning. Symptoms may be new onset following initial recovery from an acute COVID-19 episode or persist from the initial illness. Symptoms may also fluctuate or relapse over time.]	Based on the evidence reviewed to date, the panel decided that no changes are currently required to the case definition. This guideline has been developed using a 'living' approach and therefore the forthcoming WHO definition may be considered in future updates. The panel concluded that the WHO definition is similar to the NICE definition, in identifying a condition usually occurring 3 months from the onset of COVID-19, which cannot be explained by alternative diagnosis. Discussion around the panel's conclusions has been added to the evidence to decision for case definition.
General	***[based on 36 comments*]**	
	Indirect evidence One stakeholder suggested that indirect evidence from related conditions such as SARS/MERS be included for extrapolation where evidence is lacking.	Indirect evidence was not used for this guideline for any review question, due to the volume of evidence and time constraints, and due to the difficulty in extrapolating indirect evidence to the new condition with uncertain pathological

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		mechanisms. Evidence for the update was only considered from the date of the guideline publication in December 2020.
	Chronic Fatigue syndrome/myalgic encephalomyelitis (CFS/ME) Several stakeholders expressed concern that CFS/ME has not been mentioned. Although this is out of scope they commented on similarities in symptoms and raised concerns that people will be considered as having post-COVID syndrome and not CFS/ME and may receive inappropriate treatment e.g. graded exercise therapy. There were several comments on the lack of recommendations on managing specific symptoms that are discussed in the draft CFS/ME guideline. These stakeholders were particularly concerned with the emphasis on rehabilitation and goal setting.	The panel discussed whether this should be added and decided that consideration of differential diagnoses was accounted for in recommendations in sections on assessment and investigations and referral, and nothing specific about CFS/ME needed to be added to the guideline. The panel discussed CFS/ME and agreed that no recommendation could be made about symptom overlap or likelihood of developing CFS/ME because not enough is known about this currently. The management of CFS/ME is outside the scope of the long term effects guideline. The panel were clear that conclusive parallels could not be drawn, and the panel were satisfied that realistic goals agreed as part of shared decision making with the patient did not mean that people should push themselves and cause harm.
	Expert Testimony Several stakeholders commented on the selection and suitability of experts for providing expert testimonies and proposed experts with other areas of expertise. Two stakeholders objected to the bullet point relating to rehabilitation services in Scotland having the "desire to not over-medicalise Long Covid" emphasising that the value of medical input, assessment, investigations and treatment should be evaluated by NICE .	The expert witnesses were nominated by the panel and invited to present testimonies by the NICE project team, in accordance with the Developing NICE guideline manual. The panel did not base its conclusions solely on expert testimonies, but these served to inform a balanced decision making process in making new or updating existing recommendations. The views of the expert testimonies do not represent the views of NICE. NICE has not stated the desire to over-medicalise the condition and advises appropriate investigations and

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		management as clinically indicated and as guided by symptoms.
	Evidence selection Several stakeholders commented on evidence included in the update evidence review and suggested additional studies for inclusion, particularly relating to signs, symptoms and prevalence.	As stated in the methods section of the guideline, for the review questions on risk factors and the prevalence of symptoms the following additional selection criteria were applied, due to the high volume of primary evidence in these areas: • highest quality systematic reviews published in 2021 covering all signs, symptoms and risk factors • large primary studies (n>10,000) not covered by included systematic reviews. This approach was approved by the expert advisory panel and follows the NICE Interim process and methods for guidelines developed in response to health and social care emergencies. The rationale for refining the approach from the original review protocol was that important primary studies should be captured by the systematic reviews, which could be supplemented by large primary studies published subsequently. Some of the included reviews have a living approach and it is anticipated that they will be updated to include important primary research in future iterations which can inform living surveillance and updating of the guideline. Studies of larger sample sizes were prioritised as being more representative of the general population. From the studies identified, the larger studies sampled over 10,000 people whilst smaller studies were clustered below this number.

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		Evidence submitted for other sections of the guideline did not meet the inclusion criteria set out in the relevant review protocols.
	Children and Young People One stakeholder proposed that the guideline should be less adult-focused and include advice specific to children, parents and young people across the different sections of the guideline. The main areas highlighted were in provision of information on vaccines, screening questionnaires used in practice, common symptoms, appropriate investigations, self-monitoring, safeguarding, transition to adult services.	The evidence on children and young people was reviewed as part of the guideline update, with amendments consequently made to recommendations and rationales across different sections of the guideline. Recommendations will be further reviewed and amended where significant differences between adults and children are identified.
	Pain assessment One stakeholder indicated the need for pain assessment and management because long term effects of COVID-19 include pain (musculoskeletal, chest/cardiac, abdominal) as predominant symptoms.	Pain assessment and management is encompassed within the holistic approach advised in the sections on assessment and management.
Identification		
1.1 [UPDATED] Give people...advice and written information…	**CONSENSUS RECOMMENDATION** Give people who have had suspected or confirmed acute COVID-19 (and their families or carers, as appropriate) advice and written information on: • the most common new or ongoing symptoms after acute COVID-19 (see the section on common symptoms) • what they might expect during their recovery, including that: ○ recovery time is different for everyone but for many people symptoms will resolve by 12 weeks	

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	○ the likelihood of developing ongoing symptomatic COVID-19 or post-COVID-19 syndrome is not considered to be linked to the severity of their acute COVID-19 (including whether they were in hospital) ○ if new or ongoing symptoms occur they can change unpredictably, affecting them in different ways at different times • how to self-manage ongoing symptomatic COVID-19 or post-COVID-19 syndrome (see the recommendations on self-management and supported self-management) • who to contact if they are worried about new, ongoing or worsening symptoms, or if they are struggling to return to work or education, especially if it is more than 4 weeks after the start of acute COVID-19.	
	[Based on 22 comments]	
	Patient information Several stakeholders commented on appropriate information to give to patients. One stakeholder questioned what information is readily available for clinicians to give. Several stakeholders suggested giving examples of the information or signposting to resources. E.g. MY COVID recovery, Long COVID Physio, RCOT and LongCovid.org Another stakeholder would welcome signposting to additional information on Long COVID-related breathlessness. The stakeholder also noted from insights work that patients are reporting that information is not being provided (51.4%) and for those that need receive information , only 7.9% said it was very helpful and 25.4% found it fairly helpful. One stakeholder suggested that all information should be co-produced with people with lived experience and representatives of diverse communities. Another stakeholder suggested this information should be standardised.	The panel were aware that there are now several resources available but decided not to add a list of specific resources as it would not be exhaustive. However, the guideline and patient information booklet link to YourCOVIDRecovery and NHS Inform which provide useful information and links to other resources.

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	Who to contact Several stakeholders suggest more clarity needs to be added on which professionals we suggest to contact e.g. if they are struggling to return to work or education, should they contact occupational therapists, vocational rehabilitation services or others.	The panel did not specify which professionals should be contacted if someone is concerned about the impact of their symptoms. This is because it will depend on the individual’s needs as well as the local resources available. However, the rationale links to resources such as YourCOVIDRecovery which provides helpful information for when people should contact their health professional.
	Wording may cause unintended consequences One stakeholder commented that “The point ‘if new or ongoing symptoms occur they can change unpredictably, affecting them in different ways at different times’ does not appear to provide useful information and may result in negative expectations and have negative health outcomes.”	Evidence from patient experience and the panel’s own experiences indicated that symptoms can fluctuate and cause anxiety. People need good information after acute COVID-19 so they know what to expect and when to ask for more medical advice. The recommendation has now been amended to remove “change unpredictably” and replaced with “fluctuate” to clarify this point.
	Risk factors One stakeholder commented that the statement “the likelihood of developing ongoing symptomatic COVID-19 or post-COVID-19 syndrome is not considered to be linked to the severity of their acute COVID-19 (including whether they were in hospital)” is too premature and potentially misleading based on the lack of evidence.	The panel agreed that this statement was still important to have in the recommendation as to avoid people being excluded based on the severity of their acute COVID-19.

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	Another stakeholder comments that emerging evidence suggests that the development of ongoing symptomatic COVID-19 is more likely in those who were treated in hospital.	
	Asymptomatic patients One stakeholder suggests that “Individuals who have been infected with SARS-CoV-2 and who have not developed acute COVID-19, but nonetheless go on to develop Long COVID/post-COVID are now well described, so this possibility should be given for medical practitioners to consider the possibility.”	Whilst the panel are aware of patients who were asymptomatic with a SARS-CoV-2 infection but go on to develop long term effects, it is difficult to identify these individuals. Whilst there are no specific recommendations for this group of people and they are out of scope, it was acknowledged that going forward, it may become possible to identify this group based on the current testing that is available. This is something that will be considered through our living approach to updating.
[NEW] Give people information on COVID-19 vaccines...	**CONSENSUS RECOMMENDATION** Give people information on COVID-19 vaccines (see NHS information on COVID-19 vaccines). Encourage them to follow current government guidance for vaccination to reduce the risk of a further acute infection but explain that it is not known if vaccines have any effect on ongoing symptomatic COVID-19 or post-COVID-19 syndrome.	
	[based on 18 comments]	
	Impact of Vaccines One stakeholder who supports the inclusion of this recommendation is concerned that the wording advising that “it is not known of the effect of vaccination on symptoms” must be done with caution so that the messages “isn’t seen to endorse any vaccine safety myths” and must not disrupt vaccine confidence. The stakeholder suggests using	The evidence on the impact of vaccines on long term effects of COVID is inconclusive, and this is reflected in the wording of the recommendation. New evidence will be monitored and reviewed through continuous surveillance as part of the living approach to maintaining the guideline.

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	wording such as “evidence is still emerging” or “there is no evidence yet to suggest an effect”. One stakeholder suggests that “Given that persons with Long COVID/post-COVID will already have been infected and developed immunity it should be pointed out that vaccination will, in effect, be boosters, so their immunity will be improved and further enhanced by vaccination. However, they will also be at greater risk of well-known and described local (e.g. Type III hypersensitivity) and systemic reactions because of their pre-existing immunity, and that if they suffer such effects it is important that these be reported via the Yellow card system to MHRA.”	
	Safety of COVID vaccines in people with Long term effects of COVID Several stakeholders were concerned that this recommendation does not reflect the lived experiences of people with Long term effects of COVID-19 who have had the vaccine. One stakeholder requested that there should be more information provided on the safety of vaccines for people experiencing long-term effects of COVID-19, or at least reassurance that research is underway, in order to reassure patients and acknowledge any side effects they may have. Another stakeholder objects to the inclusion of this recommendation due to the lack of information on the safety of the vaccine in people with Long COVID. The stakeholder reported that many people in support groups report mostly negative impacts of the vaccines. One stakeholder highlighted that in France, pre-existing active myocarditis or pericarditis (which are reported in Long COVID) are	The evidence on the impact of vaccines on long term effects of COVID is inconclusive, and this is reflected in the wording of the recommendation. New evidence will be monitored and reviewed through continuous surveillance as part of the living approach to maintaining the guideline. The text of the recommendation has been amended to state that vaccination should be encouraged in line with current national guidance, which provides for known contraindications and safety issues.

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	considered to be vaccine contraindications. The stakeholder also states that cardiologists in London are also following this advice. One stakeholder suggested that the recommendation should ensure that people are aware that symptoms may temporarily improve or worsen following vaccination. They also suggest that there should be advise on the risk of impact on “menstrual cycle length, flow or symptoms, as increased pain in particular is likely to exacerbate post-COVID-19 syndrome.”	
	Vaccines in children Several stakeholders highlighted that this recommendation should state that vaccines should be encouraged in line with current guidance.	The text of the recommendation has been amended to state that vaccines should be encouraged in line with current national guidance, which provides official advice for different age groups.
1.2 [UPDATED] Provide all information in accessible formats...	**INFO BOX** Provide all information in accessible formats so that people can understand and take part in decisions about their care. Follow relevant national guidance on communication, providing information (including different formats and languages) and shared decision making, for example: • NICE’s guidelines on patient experience in adult NHS services and shared decision making • Healthcare Improvement Scotland's website ‘What Matters To You’. **REMARK** NICE, RCGP and SIGN's patient booklet on Long COVID provides accessible information for people who have had a COVID-19 infection and have ongoing signs and symptoms.	
	[based on 15 comments]	

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	Sources available in multiple languages One stakeholder commented that providing information in multiple languages is not feasible if not available. Another stakeholder noted that "World Physiotherapy" information sheets are freely available in up to 60 different languages, with 5 information sheets on Long COVID.	The recommendation encourages provision of patient information in accessible formats. Whilst not all information is available in multiple languages, the best available format should be provided based on the needs of the patient.
	Accessible formats One stakeholder suggested more clarity on what we mean by accessible formats and requires guidance on how this information is drafted. One stakeholder highlighted that people with cognitive impairment and "brain fog" may have difficulty accessing information in apps, electronic devices or have difficulties comprehending spoken or written language.	The recommendation has now been amended to signpost to NHS England's Accessible information standard to provide clarity on what is meant by accessible formats. When providing information, the best available format should be given based on the needs of the patient.
1.3 [UPDATED] For people with new or ongoing symptoms…	**CONSENSUS RECOMMENDATION** For people with new or ongoing symptoms after acute COVID-19, suspect: • ongoing symptomatic COVID-19 if people present with symptoms 4 to 12 weeks after the start of acute COVID-19 **or** • post-COVID-19 syndrome if the person's symptoms have not resolved 12 weeks after the start of acute COVID-19.	
	[based on 13 comments]	
	Pre-COVID symptoms	

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	One stakeholder highlighted the need to establish whether symptoms are in fact new and were not present before the patient experienced acute COVID illness. “Some patients are presenting to primary care with symptoms that existed prior to COVID-19 and these symptoms risk being attributed to post-COVID syndrome unless this is specifically considered”.	The recommendation under the assessment section for using holistic, person-centred approaches to assessment has now been updated to include “exacerbation of pre-existing conditions” as something to cover in the comprehensive clinical history.
	Other diagnoses Several stakeholders raised the need to include considering other diagnoses at this point.	The purpose of this recommendation is to encourage consideration of ongoing symptomatic COVID-19 and post-COVID-19 syndrome as part of the differential diagnosis. Recommendations for assessment, investigations and referral highlight the importance of considering other diagnoses alongside ongoing symptomatic COVID-19 and post-COVID-19 syndrome. The rationale for the recommendation has been amended to clarify this.
1.4 [UPDATED] For people who are concerned... offer an initial consultation	**CONSENSUS RECOMMENDATION** For people who are concerned about new or ongoing symptoms 4 weeks or more after acute COVID-19, offer an initial consultation and use shared decision making to discuss and agree with the person whether it should be remote or in person.	
	[based on 13 comments]	
	Initial consultation One stakeholder requested greater clarity on which professionals are best placed to carry out an initial consultation based on the person’s	The panel acknowledged that there is not a specific healthcare professional who could carry out the initial assessment. This is because it depends on local resources and care pathways.

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	presenting needs and priorities. “As well as general practitioners and nurses, this may also be an occupational therapist, physiotherapist or psychologist.”	
	Shared decision-making One stakeholder raised concerns that the expert testimony text implies there is a move towards “emphasising the potential for shared decision making to ‘alleviate anxiety’, … could be interpreted as there is no need to do investigations”. Other stakeholders have also commented that the expert testimony is implying that we should be moving away from investigations. Another stakeholder stated that the recommendations should be clear in indicating that “in-depth consultations should occur in addition to and not instead of clinical tests, which are important in helping to exclude other respiratory conditions for people presenting with Long COVID-related breathlessness”. One stakeholder disagreed that “people living with Long COVID are anxious due to unnecessary or over investigation”. Instead they asserted that “People with Long COVID are reporting they may experience uncertainty or anxiety associated with not having symptoms investigated or not having their symptoms believed”.	The panel were concerned that over-investigating would not be helpful to patients. Therefore, they encourage the use of shared decision-making to determine patient preferences. Additional text has been added to the rationale to explain that this discussion aims to determine which are the most appropriate tests to carry out.
	Timeframe One stakeholder suggests removing the “4 week” timeframe from this recommendation as to not exclude people presenting with serious symptoms earlier.	The scope of the guideline covers people who present with new or ongoing symptoms that they experience 4 weeks of more after acute COVID-19. If someone presents with serious symptoms earlier than 4 weeks, they should be managed within the acute COVID-19 pathway.
	Remote vs face to face appointments	

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	Several stakeholders suggested that if people are experiencing chest pain and breathlessness, these should always be assessed face to face. Another stakeholder suggested that where virtual appointments are offered, there should be sufficient technology in place. Several stakeholders commented that the initial consultation should really be a face to face consultation with a discussion about whether further appointments can be done remotely.	Whilst the panel acknowledge that some circumstances require face to face appointments, they encourage the use of shared decision-making to determine what would be best. This would include discussions around the technology used in the context of virtual appointments and what patient preferences are.
1.6 [UPDATED] Some people...may not have the most commonly reported new or ongoing symptoms...	**INFO BOX** Some people (including children and older people) may not have the most commonly reported new or ongoing symptoms after acute COVID-19. **REMARK** The following symptoms and signs are less commonly reported in children and young people than in adults: • shortness of breath • persistent cough • pain on breathing • palpitations • variations in heart rate • chest pain.	
	[based on 19 comments]	
	Rationale for this recommendation One stakeholder suggested that this information is not helpful as there is no guidance on what should be done if these less common symptoms arise e.g. should an alternative diagnosis be considered?	The panel agreed it was important that uncommon symptoms in children are highlighted here to ensure that a child or young person presenting with these symptoms may be more likely to have a different diagnosis. Text has now been added to this information box to clarify “The following symptoms

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	Several stakeholders also highlighted the need to list the common symptoms rather than the uncommon symptoms for CYP. Other stakeholders highlighted that listing the uncommon symptoms in CYP may lead a degree of dismissiveness even those these symptoms do still occur.	and signs are less commonly reported in children and young people than in adults and should be investigated for alternative diagnoses”.
[NEW] In addition to clinical symptoms...	**INFO BOX** In addition to clinical symptoms, be aware that people who report increased absence or reduced performance in their education, work or training after acute COVID-19 may have ongoing symptomatic COVID-19 or post-COVID-19 syndrome.	
	[based on 15 comments]	
	Indicators of Post COVID-19 syndrome Several stakeholders highlighted that “people who report increased absence or reduced performance in their education, work or training after acute COVID-19” may be attributed to other diagnoses or other reasons e.g. bereavement, pandemic effects, not necessarily post COVID-19 syndrome which this recommendation implies. Another stakeholder highlighted that the ability to participate in education, work and training are not the only functional indicators that a person may have. They may also have “reduced ability to complete a wide range of daily activities, and the impact of this may be significant for their independence and psychological wellbeing”. This also includes exercise, socialising and enjoyable activities. Another stakeholder	Whilst increased absence or reduced performance in education, work and training may be attributed to other diagnoses or other reasons, the panel wanted to flag these as other potential indicators of ongoing symptomatic COVID-19 or post-COVID-19 syndrome and should form part of the considerations in a differential diagnosis.

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	suggests that “cognitive dysfunction” should be added to this recommendation. Another stakeholder pointed out that clarity is needed on the baseline measurement that is being compared to in this recommendation.	
1.7 [UPDATED] Based on the initial consultation, use shared decision making…	**CONSENSUS RECOMMENDATION** Based on the initial consultation, use shared decision making to discuss and agree with the person whether they need a further assessment and whether this should be remote or in person. Take into account whether they may have symptoms that need investigating in person or require urgent referral to an appropriate service.	
	[based on 16 comments]	
	Shared decision-making One stakeholder commented that “there needs to be acknowledgement of how all service users can be supported with shared decision making including those with a learning disability and neurodiverse individuals”. Another stakeholder suggested that “True sharing of the decisions to be taken must ensure that the patient has adequate knowledge of the available options and consequences. Without this and without an awareness of the patient's values and preferences there is likely to be dissatisfaction with the choices made and perhaps a lack of adherence to suggested actions.”	For clarity on shared decision-methods, this recommendation has now been amended to signpost to NICE’s guidelines of shared decision-making, decision-making and mental capacity and Healthcare Improvement Scotland’s website ‘What matters to you’.
	Face to face assessment One stakeholder raised concerns that this recommendation implies “that urgent referrals do not require a face-to-face assessment”	Whilst the panel acknowledged that some circumstances require face to face appointments, they encouraged the use of shared decision-making to determine what would be best. This would include discussions around the technology used in

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	Another stakeholder highlighted that children should not be assessed remotely if they have been identified as missing education as this is a safeguarding concern.	the context of virtual appointments and what patient preferences are. The rationale has been updated to say, “the panel agreed that decisions about whether consultations should be remote or in person should always take into account any safeguarding concerns.”
1.10 [UPDATED] A healthcare professional in secondary care…	**CONSENSUS RECOMMENDATION** A healthcare professional in secondary care should offer a follow-up consultation at 6 weeks after discharge to people who have been in hospital with acute COVID-19 to check for new or ongoing symptoms or complications.	
	[based on 15 comments]	
	Follow up in secondary care One stakeholder suggested that this recommendation is nebulous and would benefit from clarity on whether this would be a virtual or physical consultation and what level of clinician this would be. Another stakeholder suggested adding “based on clinical need using shared decision-making” due to concerns about feasibility. This was supported by another stakeholder who suggests that the emphasis of this follow-up would be to pick up the red flag issues and to reassure regarding ongoing symptoms. One stakeholder suggested providing a 6-12 week window “as many patients make a full recovery with self – management within the first 12 weeks – this approach maximises the use of the consultation and any onward referrals. In contrast, another stakeholder suggested that a digital follow-up (email/text) could be sent to everyone after a positive test.	The panel chose to not specify whether this consultation should be face-to-face or virtual because it should be based on joint patient and clinician preferences decided upon discharge. They felt strongly that this appointment should occur at 6 weeks in order to identify new symptoms and complications at an optimal time after discharge. If further consultation is required, it is expected that action is taken according to the recommendations in the identification and assessment sections. There is a similar recommendation for vulnerable and high-risk groups who have been managed for acute-COVID-19 in primary care so that they are followed up accordingly. This is a ‘consider’ recommendation as not every patient in primary care will necessarily need this kind of follow-up.

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	One stakeholder added that a person-centred approach should be used to “ensure that people from diverse communities are reached appropriately and effectively and are receiving an equitable level of support”. Another stakeholder commented that people who have not been in hospital may require secondary care and are therefore excluded from this recommendation. One stakeholder raised concerns that this recommendation implies that just one consultation is needed where a single follow-up may not provide a real picture for those whose symptoms are fluctuating. Several stakeholders queried why this is an “offer” recommendation but the primary care equivalent is a “consider” recommendation especially where those in the community may have been worthy of a hospital admission but did not get admitted.	
Assessment		
2.6 (supporting remark added)	**CONSENSUS RECOMMENDATION** For people who may benefit from support during their assessment, for example to help describe their symptoms, include a family member or carer in discussions if the person agrees. **REMARK** For more advice on supporting adults to make their own decisions if they may lack mental capacity, see NICE's guideline on decision making and mental capacity and the Adults with Incapacity Act (Scotland) (2000), with further guidance available from the Mental Welfare Commission for Scotland.	
	[Based on 5 comments]	

Scope area	Key comments	Panel considerations and responses
	One stakeholder commented that patients use advocates for many reasons and it shouldn't be assumed it is a mental health issue. Another stakeholder commented that people may have capacity to make some decisions but struggle with more complex decisions.	The recommendation covers all people who may benefit from support during their assessment, which could include, but is not limited to, people who may lack mental capacity. The intention of the supporting remark is to provide links to further guidance specifically on supporting adults to make their own decisions if they may lack mental capacity.
Investigations and referral		
General	***Resource issues*** One stakeholder highlighted that the amount of resourcing required to conduct assessments and referrals is considerable, and without a triaging of who to refer and when this should be escalated, the stakeholder expressed concern that the current system could be easily overwhelmed.	There was not enough evidence to recommend specific criteria for referral and the panel agreed the right level of care would be agreed in shared decision making with the person after their holistic assessment. Resources needed are a local implementation issue. The panel acknowledged the potential implementation issues around the pressure on local resources but concluded that the recommendations were best practice and should be aimed for.
3.1 and 3.2 (re-ordered) **Offer tests and investigations tailored to people's signs and symptoms…**	**CONSENSUS RECOMMENDATION** Offer tests and investigations tailored to people's signs and symptoms to rule out acute or life-threatening complications and find out if symptoms are likely to be caused by ongoing symptomatic COVID-19, post-COVID-19 syndrome or could be a new, unrelated diagnosis. **CONSENSUS RECOMMENDATION** Refer people with ongoing symptomatic COVID-19 or suspected post-COVID-19 syndrome urgently to the relevant acute services if they have signs or symptoms that could be caused by an acute or life-threatening complication, including (but not limited to): • severe hypoxaemia or oxygen desaturation on exercise • signs of severe lung disease	

Scope area	Key comments	Panel considerations and responses
	- cardiac chest pain - multisystem inflammatory syndrome (in children).	
	[Based on 15 comments]	
	Speech and language problems One stakeholder proposed inclusion of tests for swallowing and voice problems in the guideline	The recommendation wording advises offering tests and investigations tailored to people's signs and symptoms, which may include swallowing and voice problems. It is not possible to list all the possible problems that may need investigation and testing.
	Eligibility for exercise testing Two stakeholders proposed inclusion of criteria for determining who is suitable/not suitable for exercise tolerance tests, given the potential harm of such tests.	The panel discussed the usefulness of carrying out a sit-to-stand test but also agreed clinical judgement would be needed because it is not suitable for everyone (for example, people with chest pain or severe fatigue). They agreed skill sharing between services could help with gaps in knowledge and that a protocol should be followed in order to carry a sit-to-stand test out safely. Example protocols are cited in the rationale, but the panel could not recommend any one protocol in particular as their effectiveness had not been reviewed.
3.4 [UPDATED] Offer blood tests if clinically indicated…	**CONSENSUS RECOMMENDATION** Offer blood tests if clinically indicated and guided by symptoms, which may include a full blood count, kidney and liver function tests, C-reactive protein, ferritin, B-type natriuretic peptide (BNP), HbA1c, and thyroid function tests.	
	[Based on 16 comments]	
	Specific tests Several stakeholders proposed that specific tests, including D-dimer and troponin, should be included in testing if they experience	The recommendation wording allows for these specific tests as part of clinically indicated investigations guided by symptoms. The panel recognised that multiple tests can be a

Scope area	Key comments	Panel considerations and responses
	respiratory symptoms/chest pain and are being seen in secondary care.	negative experience for some people and may not always be needed to inform management of the person's symptoms. They agreed that testing should be used as needed to supplement a detailed holistic assessment. The tests included in the text are listed as examples and are not exhaustive.
Relocated: **Consider supported self-monitoring at home...**	**CONSENSUS RECOMMENDATION** Consider supported self-monitoring at home, if this is agreed through shared decision making as part of the person's assessment. This may include heart rate, blood pressure, pulse oximetry or symptom diaries. Ensure that people have clear instructions on how to use any equipment and parameters for when to seek further help.	
	[Based on 15 comments]	
	Suitability of self-monitoring Several stakeholders emphasised that self-monitoring should only be recommended if it is appropriate for the individual, following discussion and as part of shared decision making, which should include assessment of capacity and ability to self-monitor accurately.	The panel recognised that self-monitoring at home can be useful and is used in practice but might not be suitable for everyone, and without the right information and support can cause unnecessary anxiety. People need good guidance to use equipment, interpret the results and understand when to contact a healthcare professional. This is reflected in the recommendations wording.
	Patient preferences and resource availability Two stakeholders noted that some patients may choose to pay privately for ongoing support or self-manage/supported self-management dependent on service provision and these patients need to be supported in these decisions and services not removed from them.	The panel noted that self-monitoring at home may be useful and dependent on patient preferences. As such, people would need guidance and support to self-manage and indications for the use of self-management are highlighted in this recommendation.
	Self-monitoring anxiety One stakeholder proposed that self-monitoring for anxiety should be indicated or introduced when self-monitoring is indicated.	The intention of the recommendation is for self-monitoring to be considered as part of shared decision making, which may include self-monitoring for anxiety if appropriate for the person.

Scope area	Key comments	Panel considerations and responses
3.7 [UPDATED] Offer a chest X-ray by 12 weeks …	**CONSENSUS RECOMMENDATION** Offer a chest X-ray by 12 weeks after acute COVID-19 only if the person has not already had one and they have continuing respiratory symptoms. Chest X-ray appearances alone should not determine the need for referral for further care. Be aware that a plain chest X-ray may not be sufficient to rule out lung disease.	
	[Based on 13 comments]	
	Underlying pathology Several stakeholders suggested placing more emphasis on the fact that even though a patient may have a clear X-ray they may still have underlying pathology. It was suggested that additional text be included to ensure cardiac causes of chest pain, cough and shortness of breath are considered and that the British Thoracic Society guidance on post hospital respiratory follow up be linked from the guideline.	The evidence suggested that not all pathology shows up on a chest X-ray so the panel agreed it should only be used as part of a holistic assessment to decide if referral or further care are needed in people with respiratory symptoms. This is reflected in the wording of the recommendation advising that Chest X-ray appearances alone should not determine the need for referral for further care and that a plain chest X-ray may not be sufficient to rule out lung disease. The panel agreed that the current text is sufficiently clear and that health care professionals would be aware of indications for investigating other underlying pathologies, including cardiac causes of chest pain. The panel also considered a link to the British Thoracic Society (BTS) guidance to be unnecessary as the BTS guidance aligns with the guideline recommendation.
3.10 [UPDATED] After ruling out acute or life-threatening complications...	**CONSENSUS RECOMMENDATION** After ruling out acute or life-threatening complications and alternative diagnoses, consider referring people to an integrated multidisciplinary assessment service or other relevant service any time from 4 weeks after the start of acute COVID-19.	
	[Based on 19 comments]	

Scope area	Key comments	Panel considerations and responses
	Alternatives to multidisciplinary assessment services Several stakeholders requested more detail of other relevant services to consider as alternatives to referring people to an integrated multidisciplinary assessment service where this may not be available	The panel discussed, based on expert testimony, that in some areas of the UK provision of an integrated multidisciplinary assessment service is not feasible and so added wording to take into account the other services that people may be referred to. Other relevant services would need to be determined by local needs and resources.
	Referral timepoint Two stakeholders expressed concern at the suggested referral at any time from 4 weeks after the start of acute Covid-19 due to the volume of unnecessary referrals it may trigger. Stakeholders acknowledged that complex patients with severe symptoms and impact after 4 weeks should not be declined by integrated multi-disciplinary teams, but stressed that many patients’ symptoms will resolve by 12 weeks and a lighter touch approach may be all that is necessary.	In the panel’s experience, the earlier people received help the more effective the interventions. The panel were also concerned that a lack of support could negatively affect people’s mental health. The strength of recommendation is only weak, reflecting that it should be considered for people who are likely to benefit most and may not apply to all people. Self-management is recommended as the starting point for treatment as advised in the management section.
3.11 [UPDATED] Do not exclude people from referral...	**CONSENSUS RECOMMENDATION** Do not exclude people from referral to an integrated multidisciplinary assessment service or for further investigations or specialist input based on the absence of a positive SARS-CoV-2 test (PCR, antigen or antibody) as long as the case definition criteria are met.	
	[Based on 10 comments] Several stakeholders reaffirmed their support for this recommendation.	
	Complex multi-system presentation	The recommendation was updated to add 'as long as the case definition criteria are met'. The panel were clear that access

Scope area	Key comments	Panel considerations and responses
	One stakeholder suggested additional wording not to exclude people who have a complex multi-systemic presentation	to services should not be restricted by the need for a positive SARS-CoV-2 test (PCR, antigen or antibody) as long as the case definition criteria are met. This would also include people who have complex multi-system presentations who meet the case definition.
Planning care		
4.1 [UPDATED] After the holistic assessment, discuss with the persona …	**CONSENSUS RECOMMENDATION** After the holistic assessment, discuss with the person (and their family or carers, if appropriate) the options available and what each involves. These should include: • advice on self-management, with the option of supported self-management (see the section on self-management and supported self-management) **and** • one of the following, depending on clinical need and local pathways: ○ support from integrated and coordinated primary care, community, rehabilitation and mental health services ○ referral to an integrated multidisciplinary assessment service ○ referral to specialist care for specific complications.	
	[Based on 16 comments]	
	Eligibility criteria for self-management and referral Two stakeholders suggested that the recommendations indicate in a clearer way, the eligibility criteria in which HCPs will determine patients who will be guided to self-manage and those who will be referred into other multidisciplinary and specialist services.	To ensure people get the right care and support, the expert panel agreed that a tiered approach could be used in which everyone gets advice for self-management, with the additional option of supported self-management if needed. People can then also be offered care from different services to match the level of their needs. The evidence review did not find evidence on eligibility criteria for determining self-management eligibility and referral into other multidisciplinary and specialist services.
	Support from multiple services Two stakeholders highlighted that if a patient is referred to specialist care, they are still likely to need support from integrated and	The wording of the recommendation was revised to allow for referral to one or more of the listed services as appropriate to the person's needs.

Scope area	Key comments	Panel considerations and responses
	coordinated primary care and that these actions in the recommendation should not be mutually exclusive.	
4.2 [UPDATED] Use shared decision making to agree…	**CONSENSUS RECOMMENDATION** Use shared decision making to agree what support and rehabilitation the person needs, including how and when it should be provided.	
	[Based on 13 comments]	
	Concurrent referral One stakeholder proposed advising concurrent referral rather than sequential testing to rule out, then refer, then test to rule out, then refer. The stakeholder also suggested setting up local services in a way to support people with concurrent testing to reduce burden of attending for testing.	The guideline advises that referral to an appropriate service, depending on local resources and pathways, should be considered any time from 4 weeks after the start of acute COVID-19. This includes referral to integrated multidisciplinary assessment services, where available, which would enable concurrent testing.
Management		
[NEW] Be aware that there is a lack of evidence on the effectiveness of pharmacological treatments…	**CONSENSUS RECOMMENDATION** **INFO BOX** Be aware that there is a lack of evidence on the effectiveness of pharmacological treatments for ongoing symptomatic COVID-19 or post-COVID-19 syndrome. However, participation in clinical trials may be an option for some people and should be encouraged where appropriate.	
	[Based on 19 comments]	
	Pharmacological treatment sub-section One stakeholder queried the positioning of the recommendation under self-management	The pharmacological treatments 'Info Box' provides information only and as such is not a recommendation. The location of this has been reviewed and the box is now located at the beginning of the management section for contextual information.

Scope area	Key comments	Panel considerations and responses
	Non-pharmacological treatments Two stakeholders proposed that the recommendation be extended to non-pharmacological treatments, including herbal remedies, psychological treatments and lifestyle modifications (e.g. dietary)	The purpose of the Info box is to highlight the lack of evidence on the effectiveness of systemic pharmacological treatments. Other treatments are covered elsewhere in the guideline and via the research recommendations.
	Ongoing trials Two stakeholders commented that this recommendation should include details of how health professionals should provide details of ongoing trials to patients.	The text of the Info Box has been revised to remove the reference to clinical trials, in view of the limited number of ongoing trials and mechanisms to enrol on these.
[NEW] Follow current national and local guidance for managing common symptoms...	**INFO BOX** Follow current national and local guidance for managing common symptoms, using established treatments.	
	[Based on 16 comments]	
	Established treatments Two stakeholders suggested that the guideline list examples of established treatments for managing common symptoms	The panel agreed that it would not be possible to list all established treatments due to the large number of these. The rationale does provide one example and it is expected that health care professionals would be familiar with established symptomatic treatments.
5.3 [UPDATED] Support people in discussions with their employers...	**CONSENSUS RECOMMENDATION** Support people in discussions with their employer, school or college about returning to work or education, for example by having a phased return. For advice on returning to work, follow national guidance, for example NICE's guideline on workplace health: long-term sickness absence and capability to work.	
	[Based on 17 comments]	
	Occupational health guidance Two stakeholders proposed that reference should be made to the Society of Occupational Medicine Covid-19 return to work guide for recovering workers and their managers.	Links have been provided to this guidance in the rationale of the recommendation.

Scope area	Key comments	Panel considerations and responses
	Work adjustments One stakeholder suggested that examples of work adjustments should be included, such as teleworking, changing job roles, flexitime	Specific examples of work adjustments are provided in national guidance for workplace health and are outside the scope of the Managing long term effects of COVID-19 guideline.
	Return to work One stakeholder commented that the guideline should acknowledge that some people may never return to work	The intention of the recommendation is to provide support for people in discussions with their employers, which would include not returning to work as a possible outcome. The signposted national guidance provides further advice in this area.
5.4 [UPDATED] Include physical, psychological and psychiatric aspects of rehabilitation…	**CONSENSUS RECOMMENDATION** Include physical, psychological and psychiatric aspects of rehabilitation to guide management. Ensure that any symptoms that could affect the person being able to start rehabilitation safely have been investigated first. See also the recommendation on multidisciplinary rehabilitation teams.	
	[Based on 17 comments]	
	Ability to start rehabilitation One stakeholder suggested including specific examples of symptoms that could affect the persons being able to start rehabilitation. e.g. heart conditions, micro embolisms, post exertional malaise.	The panel agreed that a rehabilitation professional should be qualified to assess and determine a person's ability to start rehabilitation without the need for specific examples to be listed, which could be too numerous to cover concisely in the guideline.
	Support Groups One stakeholder proposed that sharing skills, knowledge and experiences across the country is essential in meeting people's needs. They suggested that support groups for Long COVID-19 clinics should be implemented.	NG188 recommendations on self-management were based on panel consensus that everyone should have self-management support and information. The panel acknowledged that patient organisations and online support groups can help to support self-management and provide

Scope area	Key comments	Panel considerations and responses
		reliable up to date information and support (e.g. NHS "Your COVID recovery").
5.5 [UPDATED] Work with the person to develop a personalised rehabilitation and management plan...	**CONSENSUS RECOMMENDATION** Work with the person to develop a personalised rehabilitation and management plan that is recorded in a rehabilitation prescription and should include: • areas of rehabilitation and interventions based on their assessment • helping the person to decide and work towards goals • how to manage their symptoms, taking into account that these may fluctuate, and what to do if symptoms return or change.	
	[Based on 22 comments]	
	One stakeholder proposed adding rehabilitation specialists to the wording to clarify responsibility, given that the only people qualified to write a rehabilitation prescription are rehabilitation specialists.	The panel agreed that in the absence of a formal qualification or accreditation for rehabilitation professionals, additional text on authorisation to write the rehabilitation prescription was not warranted.
	Goal setting One stakeholder proposed inclusion of the role of pacing and to acknowledge that goals can be quite simple things such as getting dressed.	The recommendation advises helping the person to decide and work towards goals as part of a personalised rehabilitation prescription. As such, these goals should be achievable and may include daily self-care activities if appropriate.
	Patient advocates One stakeholder proposed that the recommendation include inviting an advocate to participate in the development of the rehabilitation and management plan, particularly vulnerable patients, patients with underlying cognitive impairment or those suffering with cognitive symptoms as part of their COVID-19 syndrome and that communication is culturally competent to meet the patient's and advocates needs.	The recommendations on identification provide advice to include additional support such as an interpreter or advocate during consultations, which would also apply to consultations to develop the rehabilitation and management plan. A link to this recommendation will be considered.
5.7 [UPDATED] Consider additional support for	**CONSENSUS RECOMMENDATION**	

Scope area	Key comments	Panel considerations and responses
people...who may be vulnerable...	Consider additional support for people with ongoing symptomatic COVID-19 or post-COVID-19 syndrome who may be vulnerable, for example older people and disabled people. Additional support may include short-term care packages, advance care planning and support with social isolation, loneliness and bereavement, if relevant.	
	[Based on 10 comments]	
	Vulnerable groups Several stakeholders agreed with the expansion of the recommendation to include vulnerable groups.	The support for the change to this recommendation is appreciated.
5.8 [DELETED] Consider referral from 4 weeks for specialist advice for children…	**CONSENSUS RECOMMENDATION** Consider referral from 4 weeks for specialist advice for children with ongoing symptomatic COVID-19 or post-COVID-19 syndrome.	
	[Based on 8 comments]	
	Referral of children and young people Several stakeholders enquired as to why this recommendation had been removed from the guideline.	The evidence on children and young people was reviewed in August 2021 and changes have been made to various sections of the guideline to reflect the panel discussions as set out in the evidence review. The panel re-considered whether this specific recommendation would no longer be needed and whether recommendations for referral for children and young people would be covered under the referral section. The panel noted that although the recommendations on referral apply to all age groups, there is limited advice across the guideline specific to children and young people. The recommendation was therefore reinstated to clarify that children should be referred for specialist advice. The panel agreed that the timepoint of 4 weeks could be removed as this is implicit in the rest of the recommendation.

Scope area	Key comments	Panel considerations and responses
Follow-up, monitoring and discharge		
6.1 [UPDATED] Agree with the person how often follow-up and monitoring…	**CONSENSUS RECOMMENDATION** Agree with the person how often follow-up and monitoring are needed, which healthcare professionals should be involved and whether appointments should be carried out in person or remotely. Take into account: • the person’s needs and the services involved • the person's symptoms, including new or worsening symptoms, and the effects of these on the person’s life and wellbeing • availability, clinical suitability and the person's preferences for in-person or remote appointments.	
	[Based on 14 comments]	
	Service provision and implementation Three stakeholders noted that there may be variations in practice across service providers in the UK and that these variations are due to differences in the availability, capacity, and delivery of the service and as such need to be captured or considered in this guideline.	NG188 aims to identify, assess, and manage the long-term effects of COVID-19. The comments received were outside the scope of the guideline as they are concerned with issues of implementation. The panel acknowledged the potential issues around the variation in services delivery being a barrier to implementation but concluded that the recommendations were best practice and should be aimed for.
	Nutritional Screening Tools One stakeholder noted that patients need to be aware of how their dietary habits have changed and practitioners should promote self-assessment and use nutritional screening tools during monitoring.	NG188 aims to identify, assess, and manage the long-term effects of COVID-19. Whilst the role of nutritional screening tools is important in monitoring the patients’ treatment journey, it may not be required for everyone. As such, this guideline, highlights how patients’ needs and requirements need to be considered when devising treatment plans for them. This may encompass a nutritional plan or regimen and it is at the clinician’s or specialist’s discretion to devise appropriate management and rehabilitation plans for them, dependent on their needs.

Scope area	Key comments	Panel considerations and responses
	Inequality considerations Several stakeholders noted that different health equality issues need to be considered when making this recommendation such as service access, carer availability, digital poverty, child safeguarding and nutritional habits of individuals.	We noted that these issues were considered in equality impact assessment (EIA) and that the EIA entails that all users be aware of underlying equality issues when considering management of long term effects and that special considerations are made to ensure equal access to services.
6.2 [UPDATED] Using shared decision making, discuss and agree plans for discharge…	**CONSENSUS RECOMMENDATION** Using shared decision making, discuss and agree plans for discharge from rehabilitation and care, taking into account the person's preferences, goals and social support.	
	[Based on 13 comments]	
	Critique of expert testimonies Two stakeholders commented that the Nuffield Health testimony does not account for people who experience post exertional malaise or exercise intolerance and promotes graded exercise therapy instead in patients with long term effects. One stakeholder noted that a study used to guide this rationale was based on the experiences of military personnel and adults; as such it cannot be used to make recommendations for children and other adults.	The Nuffield Health testimony was not considered in isolation and was considered alongside 2 other expert testimonies in informing the panel discussion. Although one testimony includes military personnel in the military population, this recommendation was made based on the combination of panel member review and expert testimonies and aims to be applicable to the entire population. The panel acknowledged that the three testimonies all had potential limitations in terms of generalisability. They therefore did not directly apply the way these programmes managed discharge in their recommendations.
	Patient considerations Two stakeholders noted that those suffering from impaired cognition, or vulnerable patients, must have considerations made to ensure that communication and shared decision making is agreed upon and patients discuss and agree with their future management/discharge plans.	The panel has made considerations for vulnerable groups in the recommendation above "Consider additional support for people with ongoing symptomatic COVID-19 or post-COVID-19 syndrome who may be vulnerable, for example older people and disabled people. Additional support may include short-term care packages, advance care

Scope area	Key comments	Panel considerations and responses
		planning and support with social isolation, loneliness and bereavement, if relevant". By updating the previous recommendation, the panel has allowed for additional support to be provided to wider groups in the population.
	Re-accessing service/support several stakeholders highlighted that it is important to discuss mechanisms for efficiently re-accessing support and services if symptoms reoccur and how patients/clinicians can aid in the identification and management of the symptoms with minimal delay and not having to go back to primary care to access treatment e.g. through non-NHS assessment, not fully discharging people, continued access to services. One stakeholder further commented that, with respect to fluctuating symptoms, early referral should be enabled into services that support an 'open referral back' policy, such as enabling access to basic advice and support at a future point if support needs increase or change.	It is recognised that symptoms may fluctuate and recur with patients needing to re-access support and services in the most efficient way possible. However, following shared decision making, local referral pathways would need to be followed due to variation in practice and funding. This will be reflected in the rationale of the recommendation.
	Occupational therapy One stakeholder suggested adding a remark to ensure good and timely access to occupational therapy assessment and aids in adaptations to alleviate post-exertional malaise and fatigue. Offer a longer appointment time is needed.	The guideline recommends that occupational therapy expertise is included as part of multidisciplinary rehabilitation services for people with post COVID-19 syndrome. This will ensure the effective and timely access to occupational therapy assessment and aids as part of the person's personalised rehabilitation plan. This will also include longer appointment times according to the person's needs.
[Amended] Be alert to symptoms developing that could mean referral or investigation is needed...	**CONSENSUS RECOMMENDATION** Be alert to symptoms developing that could mean referral or investigation is needed, following recommendations in the section on assessment.	
	[Based on 17 comments]	
	Clarification on audience of recommendation	The rationale for the recommendation states that the panel agreed that healthcare professionals should be alert to any

Scope area	Key comments	Panel considerations and responses
	Three stakeholders suggested that the wording of the recommendation needs to specify who needs to be alerted to avoid ambiguity.	changes and that the recommendations in the assessment section would also apply to monitoring.
	Recurrence of symptoms Two stakeholders affirmed that patients need to be confident and aware of any changes in symptoms, recurrence of symptoms and how to report them in line with this guideline.	The recommendation in the identification section on provision of advice and information to people who have had suspected or confirmed acute COVID-19 includes advising people that if new or ongoing symptoms occur they can change unpredictably, affecting them in different ways at different times, and who to contact if they are worried about new, ongoing or worsening symptoms
	Capturing unpredictable nature of Long term effects of COVID-19 Two stakeholders suggested the wording for this recommendation be changed e.g., "Be alert to symptoms developing over the trajectory of living with long COVID-19…", to capture the multidimensional, episodic, and unpredictable nature of Long COVID-19.	The case definition for post COVID-19 syndrome captures the multidimensional, episodic, and unpredictable nature of the condition: Signs and symptoms that develop during or after an infection consistent with COVID-19, continue for more than 12 weeks and are not explained by an alternative diagnosis. It usually presents with clusters of symptoms, often overlapping, which can fluctuate and change over time and can affect any system in the body. Post-COVID-19 syndrome may be considered before 12 weeks while the possibility of an alternative underlying disease is also being assessed.
Service organisation		
8.1 [UPDATED] Provide access to	**CONSENSUS RECOMMENDATION** Provide access to multidisciplinary services (these could be 'one-stop' clinics) for assessing physical and mental health symptoms and carrying out further tests and investigations. Services should be led by a doctor with relevant skills and experience and appropriate specialist support, taking into account the variety of presenting symptoms.	

Scope area	Key comments	Panel considerations and responses
multidisciplinary services…for assessing...	***[Based on 15 comments]***	
	"One-Stop" COVID-19 Clinic Several stakeholders highlighted the benefit and importance of a "one-stop" COVID-19 clinic, and the creation of one MDT comprised on various healthcare professionals, would be ideal in streamlining the patient clinical pathway. One stakeholder recommended that the term "multidisciplinary" (MDT) Clinic would be preferable to "One-Stop" clinic, as the patient with long COVID-19 requires an MDT approach to care and input, and the term MDT is more reflective in differences in service delivery models across the UK.	Different regional and geographical challenges mean that areas have different service needs and resources, so the panel agreed that one model would not fit all areas. The panel agreed a multidisciplinary service for assessment could avoid multiple referrals and would provide a single point for care. This could be a 'one-stop' clinic to help keep appointments to a minimum, although this might not be feasible for all services or wanted by all patients. The recommendation uses the wording 'multidisciplinary' but mentions 'One-Stop clinics' as a colloquial term for this.
	Co-ordination of MDT/One-stop Clinics Three stakeholders proposed that there needs to be a clear strategy on who will lead these clinics, what specialists the MDT will be comprised on and how to tailor existing services to cope with the evolving long term effects landscape.	The guideline focuses on assessing, managing and follow-up of long term effects. Comments on technical and strategical service delivery are outside the scope of this guideline as they vary between regions and trusts and are dependent on health service policy which is outside the remit of NICE.
	Equality Considerations Two stakeholders noted that there are health inequality drivers that contribute to varying disease presentation and illness trajectory. E.g., stereotypes surrounding different demographics such as BAME, access to resources in different trusts and local policy differences.	The EIA within NG188 recognises various contributors and drivers of health inequality and attempts to minimise their impact. It is important to consider the impact of these factors on access to service and health equity. This has been considered in EIA of NG188 at every step of guideline development.
	Service Provision/ Delivery Several stakeholders noted that there may be barriers to service delivery, implementation, and access across the UK; especially in	NG188 focuses on the assessment, management, and follow-up of long term effects for patients. Service provision and delivery are outside the scope of this guideline and fall within the remit of implementation authorities.

Scope area	Key comments	Panel considerations and responses
	devolved governments in Wales/Scotland, and the current state of the NHS in England.	
8.2 [SUPPORTING REMARK ADDED] Additional expertise should be provided according to the person's needs...	**CONSENSUS RECOMMENDATION** Provide integrated, multidisciplinary rehabilitation services, based on local need and resources. Healthcare professionals should have a range of specialist skills, with expertise in treating fatigue and respiratory symptoms (including breathlessness). Additional expertise may be needed depending on the age and symptoms of the person. The core team could include, but not be limited to, the following specialist areas: • occupational therapy • physiotherapy • clinical psychology and psychiatry • rehabilitation medicine. **REMARK** Additional expertise should be provided according to the person's needs. Other areas of expertise could also include, but are not limited to, rheumatology, neurology rehabilitation, cardiology, paediatrics, dietetics, speech and language therapy, nursing, pharmacy and support to return to education or work.	
	[Based on 14 comments]	
	MDT Core Members/Specialists Several stakeholders noted that the MDT should be comprised of various occupational health specialists alongside those listed, most importantly doctors. The stakeholders suggested that doctors with relevant expertise and cross speciality knowledge should lead these clinics and should be named as the overall lead, to aid with coordination of care.	The comment is consistent with the recommendation and the additional remark added.
	Speech and Language Therapists Three stakeholders emphasised the importance and pertinence of speech and language therapists, in the recovery and clinical pathway of patients and how this guideline highlights their role and importance.	The comment is consistent with the recommendation and the additional remark added, which incorporates speech and language therapist expertise according to the person's needs.

Scope area	Key comments	Panel considerations and responses
8.4 [UPDATED] Agree local, integrated referral pathways…	**CONSENSUS RECOMMENDATION** Agree local, integrated referral pathways between primary and community care, rehabilitation services and specialist services, multidisciplinary assessment clinics (where available) and specialist mental health services.	
	[Based on 9 comments]	
	Third/Community Sector Support Two stakeholders proposed that input from third sector organisations and the community needs to be considered to ensure success of this pathway.	In the planning care section, the guideline advises, depending on clinical need and local pathways, support from integrated and coordinated primary care, community, rehabilitation and mental health services which would encompass third sector organisations and the community.
	Identification of unified point of care/contact Two stakeholders suggested that a central or clear point of care/contact needs to be named to ensure integrity of the pathway and that best recommendations are made for individuals.	This recommendation sets out how patients should be managed throughout the clinical pathway and recommends key specialists or stakeholders that may be involved in patient care. The recommendation advises on best practice for most patients; however, it cannot account for variations of practice between different patients, different regions, and different policies. As such, there may be variations in practice that arise at the practitioner's discretion based on the individuals' needs. This guideline emphasises the importance of shared decision making and involving patients in their care, so that patients are empowered and supported in making decisions and advocating for their needs as well as ensuring the continuity of their care.
	Patient and Clinician Support Two stakeholders recognised that primary care providers need to be supported to implement these referral pathways, as well as patients being supported and not missing out on service access.	NG188 addresses assessment, management, and follow-up of patients with long term effects. During discussions, the panel noted that there are service access and implementation issues that become apparent due to the nature of the health system and landscape in the UK. The panel also noted and emphasised the role that primary care plays in accessing

<table>
<tr><th>Scope area</th><th>Key comments</th><th>Panel considerations and responses</th></tr>
<tr><td></td><td></td><td>services related to COVID-19 and unrelated to it alike. However, for the safe management of patients, the panel felt that primary care providers are still an important point of care and patients should go through the relevant clinical pathway to investigate their symptoms. NG188 emphasises that patients should also be involved and supported in making decisions around their care which may play a role in them re-accessing services in case there is a relapse of symptoms. Outside of that, this recommendation cannot comment on implementation issues as they vary between regions, organisations and local policy.</td></tr>
<tr><td></td><td></td><td></td></tr>
<tr><td>Common symptoms</td><td colspan="2">INFO BOX
Symptoms after acute COVID-19 are highly variable and wide ranging. The most commonly reported symptoms include (but are not limited to) the following:</td></tr>
<tr><td rowspan="3">[UPDATED] Neurological symptoms</td><td colspan="2">INFO BOX
• Cognitive impairment (‘brain fog’, loss of concentration or memory issues)
• Headache
• Sleep disturbance
• Peripheral neuropathy symptoms (pins and needles and numbness)
• Dizziness
• Delirium (in older populations)
• Mobility impairment
• Visual disturbance</td></tr>
<tr><td>[Based on 9 comments]</td><td></td></tr>
<tr><td><i>Dysautonomia</i></td><td>The common symptoms list is derived from the most reported symptoms in the evidence and is not exhaustive. The list is prefaced by text to reflect this.</td></tr>
</table>

Scope area	Key comments	Panel considerations and responses
	Two stakeholders suggested dysautonomia be considered as a neurological symptom as it related to a cluster of symptoms in the body with long term effects.	
	Post-exertional malaise Five stakeholders proposed that post-exertional malaise and menstrual symptoms be included in the list of common symptoms	The common symptoms list is derived from the most reported symptoms in the evidence and is not exhaustive. The list is prefaced by text to reflect this.
	Further neurological symptoms One stakeholder suggested that neuropathic pain, dizziness (vertigo) and executive function in cognitive dysfunction	The common symptoms list is derived from the most reported symptoms in the evidence and is not exhaustive. The list is prefaced by text to reflect this.
	Role of Speech and language therapy One stakeholder noted that NG188 captures the role of speech and language therapists in the management of long term effects and the symptoms.	The stakeholder's support for the guideline is acknowledged.
[UPDATED] Gastrointestinal symptoms	**INFO BOX** • Abdominal pain • Nausea and vomiting • Diarrhoea • Weight loss and reduced appetite	
	[Based on 6 comments]	
	Acid reflux Three stakeholders proposed that acid reflux be added as a symptom.	The common symptoms list is derived from the most reported symptoms in the evidence and is not exhaustive. The list is prefaced by text to reflect this.

Scope area	Key comments	Panel considerations and responses
	Polyuria/polydipsia One stakeholder proposed that polyuria/polydipsia be included to list of common symptoms.	The common symptoms list is derived from the most reported symptoms in the evidence and is not exhaustive. The list is prefaced by text to reflect this.
	Dysautonomia and relationship with other systems Two stakeholders noted that dysautonomia symptoms such as acid reflux, indigestion, persistent bowel disturbance and increased sensitivity to certain foods need to be added to the list of common symptoms.	The common symptoms list is derived from the most reported symptoms in the evidence and is not exhaustive. The list is prefaced by text to reflect this.
[UPDATED] Psychological/psychiatric symptoms	**INFO BOX** • Symptoms of depression • Symptoms of anxiety • Symptoms of post-traumatic stress disorder	
	[Based on 5 comments]	
	Low mood Two stakeholders suggested that low mood should be added as a symptom and specified.	The list of psychological symptoms specifies that symptoms of depression and anxiety are common in long term effects. As low mood is a common symptom between depression and anxiety, it is already covered by the list of symptoms.
	Considerations for children One stakeholder noted that considerations for children PANS/PANDAS needs to be highlighted in symptom list. One stakeholder highlighted that the evidence suggests that secondary age children with PIMS-TS report symptoms of hoarse voice, dysphonia and speech and language difficulties.	The common symptoms list is derived from the most reported symptoms in the evidence and is not exhaustive. The list is prefaced by text to reflect this.

Scope area	Key comments	Panel considerations and responses
[UPDATED] Ear, nose and throat symptoms	**INFO BOX** • Tinnitus • Earache • Sore throat • Dizziness • Loss of taste and/or smell • Nasal congestion	
	[Based on 6 comments]	
	Tinnitus One stakeholder commented that tinnitus can be pulsatile in nature and to include other symptoms like swallowing difficulties and feelings of pressure in the head.	The common symptoms list is derived from the most reported symptoms in the evidence and is not exhaustive. The list is prefaced by text to reflect this.
	Eye symptoms One stakeholder suggested that eye symptoms should be added	The common symptoms list is derived from the most reported symptoms in the evidence and is not exhaustive. The list is prefaced by text to reflect this.
	Mouth ulcers and COVID-19 tongue One stakeholder suggested that mouth ulcers and COVID-19 tongue should be added to symptom list.	The common symptoms list is derived from the most reported symptoms in the evidence and is not exhaustive. The list is prefaced by text to reflect this.
	Changes to taste and smell Two stakeholders noted that loss of taste and smell should be changed to changes to taste and/or smell.	The common symptoms list is derived from the most reported symptoms in the evidence and is not exhaustive. The list is prefaced by text to reflect this.
	Vertigo Two stakeholders noted that dizziness should be replaced with vertigo as it is more clinically appropriate	The common symptoms list is derived from the most reported symptoms in the evidence and is not exhaustive. The list is prefaced by text to reflect this.

<table>
<tr><th>Scope area</th><th>Key comments</th><th>Panel considerations and responses</th></tr>
<tr><td></td><td></td><td></td></tr>
<tr><td></td><td></td><td></td></tr>
<tr><td rowspan="6">[UPDATED] Dermatological symptoms</td><td colspan="2">INFO BOX
• Skin rashes
• Hair loss</td></tr>
<tr><td><i>[Based on 5 comments]</i></td><td></td></tr>
<tr><td><i>Vertigo</i>
One stakeholder noted that facial flushing should be added to the symptom list.</td><td>The common symptoms list is derived from the most reported symptoms in the evidence and is not exhaustive. The list is prefaced by text to reflect this.</td></tr>
<tr><td><i>Further symptoms</i>
One stakeholder suggested that the symptom list is expanded and elaborated to include newer dermatological reactions.</td><td>The common symptoms list is derived from the most reported symptoms in the evidence and is not exhaustive. The list is prefaced by text to reflect this.</td></tr>
<tr><td><i>Itchy skin</i>
Two stakeholders proposed that itchy skin should be included in the symptom list.</td><td>The common symptoms list is derived from the most reported symptoms in the evidence and is not exhaustive. The list is prefaced by text to reflect this.</td></tr>
<tr><td><i>COVID-19 Toes/fingers/skin/nails</i>
Two stakeholders suggested that COVID-19 toes and fingers, peeling skin, brittle/discoloured nails should also be added to the symptom list.</td><td>The common symptoms list is derived from the most reported symptoms in the evidence and is not exhaustive. The list is prefaced by text to reflect this.</td></tr>
<tr><td></td><td></td><td></td></tr>
<tr><td>[NEW] Comment on symptoms that are less</td><td colspan="2">REMARK
Be aware that the following cardiac and respiratory symptoms and signs are less common in children and young people than in adults:</td></tr>
</table>

Scope area	Key comments	Panel considerations and responses
common in children and young people	• shortness of breath • persistent cough • pain on breathing • palpitations • variations in heart rate • chest pain	
	[Based on 9 comments]	
	Common symptoms in children Several stakeholders suggested that instead of identifying which adult symptoms are less common in children, a list that identifies which symptoms are more common in children is essential.	The evidence reviews for symptoms in children evaluated a range of studies that reported symptomology in young children. However, the panel noted that there is insufficient evidence to conclusively state which symptoms are more common in children than adults and as such this recommendation was made, with the consideration and caveat that the common symptoms list is not exhaustive. The absence of a symptom from the list does not diminish its impact on the person. Based on many factors, patients can and will present with varying symptoms. As such, this area is kept under close review and monitoring for when further evidence emerges that can confirm common symptoms in children.
	Research recommendation One stakeholder proposed that a research recommendation is made to explore prevalence and effectiveness of interventions in children.	The research recommendations included in NG188 attempt to capture gaps surrounding prevalence and interventions in both adults and children, amongst varying other population groups. As such, the current research recommendations have already proposed the themes of prevalence and effectiveness of interventions in children as research areas.
	Voice problems in children One stakeholder stated that voice problems have been reported in secondary age children and should be captured in the symptom list.	The common symptoms list is derived from the most reported symptoms in the evidence and is not exhaustive. The list is prefaced by text to reflect this. As part of the evidence

Scope area	Key comments	Panel considerations and responses
		review, we have evaluated some studies that looked at common symptoms in children, however, no significant evidence was found to validate higher prevalence of certain symptoms in children.
	Variation in heart rate in children One stakeholder suggested that variations in heart rate be included in the symptom list as it is a common cardiovascular presentation	The common symptoms list is derived from the most reported symptoms in the evidence and is not exhaustive. The list is prefaced by text to reflect this. As part of the evidence review, we have evaluated some studies that looked at common symptoms in children, however, no significant evidence was found to validate higher prevalence of certain symptoms in children.
Research recommendations		
New suggestions	For patients who survived critical illness following COVID-19 infection, (how) does post-intensive care syndrome (PICS) differ from post-COVID-19 syndrome? How does PICS after COVID-19/post-COVID-19 syndrome differ from PICS following other similar conditions causing critical illness (e.g. community acquired pneumonia, influenza etc)?	The panel agreed that PICS is out of scope of the guideline and that the proposed research recommendations would be of more relevance to the PICS patient pathway. As such the panel did not consider it necessary to add research recommendations in this area.
	Vaccines as treatment One stakeholder suggested the inclusion of vaccines as a treatment as a new research recommendation.	The therapeutic effect of vaccines was included in the evidence review for the guideline update and in the light of current and ongoing research in this area the panel did not consider a new research recommendation to be necessary.

Scope area	Key comments	Panel considerations and responses
		The existing research recommendation on interventions for managing post-COVID-19 syndrome would also encompass vaccines in this context.
	Early interventions ***One stakeholder highlighted a gap in lifestyle and diet research at the onset of post-COVID-19 syndrome and the need for this to be addressed.***	The existing research recommendations on the most clinically effective interventions for, and early exercise rehabilitation for managing post-COVID-19 syndrome encompass early interventions such as lifestyle and diet research. As such the panel did not consider it necessary to add a specific research recommendation in this area.
	Population groups One stakeholder suggested the inclusion of research recommendations on children, particularly young children under 10 years, and for treatments in children in general. One stakeholder suggested the inclusion of research recommendations on pregnant women, highlighting the lack of research in this area.	Both children and pregnant women were considered as population groups that should be prioritised for research in the existing research recommendations and are listed as examples groups that should be considered in research on prevalence, presentation and interventions.
[DELETED] Risk factors for post COVID-19 syndrome	[Based on 5 comments]	
	Risk factors Two stakeholders disagreed with the removal of the research recommendation, highlighting the importance of understanding what factors may predispose an individual to develop long term effects, especially as there is little understanding of these and of what impact early intervention could have on the disease progression. One stakeholder asserted that the impact of pre-existing conditions should be investigated, such as asthma which has been reported as a risk factor.	There is completed and ongoing research in this area triggered by the initial research recommendation and the panel agreed that it was not as important as the other research recommendations. Furthermore, the panel agreed that if too much emphasis is placed on risk factors, people without risk factors may be overlooked.
	[Based on 7 comments]	

Scope area	Key comments	Panel considerations and responses
[UPDATED] Prevalence of post-COVID-19 syndrome	***Prevalence of Post COVID-19 syndrome*** One stakeholder agreed with the research recommendation but suggested exploring causes such as genetic susceptibility, social factors, behaviour and highlighted the need for more research into gendered, sex based differences in post-COVID-19 syndrome.	The research recommendation on prevalence incorporates variability across different population groups. The research recommendation on risk factors, including the predisposing factors suggested by the stakeholder, was withdrawn because there is completed and ongoing research in this area triggered by the initial research recommendation and the panel agreed that it was not as important as the other research recommendations. Furthermore, the panel agreed that if too much emphasis is placed on risk factors, people without risk factors may be overlooked.
[NEW] What pathophysiological mechanism(s) underlie the most common presentations of post-COVID-19 syndrome?	***[Based on 9 comments]***	
	Several stakeholders agreed with recommending research in this area. One stakeholder commented that disordered coagulation in particular is an important component of the pathophysiology. Another stakeholder commented that the research recommendation should include pathophysiological mechanisms that underline exercise intolerance among people living with Long COVID experiencing the symptom of post-exertional symptom exacerbation.	The research recommendation encompasses the areas highlighted by the stakeholders.
Equalities impact assessment	***[based on 12 comments]***	The equalities issues raised at consultation were discussed by the panel and details of how they have been addressed are included in section 14.4 of the EIA.
Sex	***Negative experiences of women*** One stakeholder notes our EIA considerations but suggests that not all have been addressed in the guideline e.g. negative experiences of women	The panel have recommended a holistic, person-centred approach when assessing somebody experiencing the long-term effects of COVID-19. This should encourage discussion around personal experiences, including negative experiences some women have encountered.
Race	None identified	

Scope area	Key comments	Panel considerations and responses
Disability	None identified	
Socioeconomic factors	None identified	
Gender reassignment	None identified	
Pregnancy and maternity	None identified	
Sexual orientation	None identified	
Carers (in relation to age and disability) **Digital accessibility**	None identified	
Other	***People with negative experiences of healthcare*** One stakeholder identified a new potential EIA consideration for people who have had negative experiences of healthcare in the past which might mean they are more reluctant to seek treatment for the long-term effects of COVID-19. The stakeholder suggests healthcare providers should reach out to these patients and ensure a supportive relationship is in place. ***People who are homeless*** One stakeholder noted that those who have no fixed abode may be lost to follow up through the healthcare system.	The panel have recommended a holistic, person-centred approach when assessing somebody experiencing the long-term effects of COVID-19. This should encourage discussion around personal experiences, including negative experiences some people have encountered. There are also two recommendations that encourage follow-up for people in vulnerable or high-risk groups (which would include people who have no fixed abode) who have been self-managed in the community or a secondary care follow-up for those people who were treated in hospital.