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 26th November to 1st December 2020. A total of 77 consultees commented, including patient involvement groups, the Royal Colleges and medical professional societies and provider and academic organisations. A total of 1066 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	*[based on 56 comments*] There was an even split between stakeholders who favoured the case definitions as presented and those who rejected them. Of these positions, the stakeholders who favoured the current approach and terminology (n=17) were predominantly from health and social care groups (with one comment from a patient group). In contrast, the stakeholders rejecting the use of the term "Post COVID-19 syndrome" and preferring "Long COVID" (n=17) were predominantly from patient groups (with a small number from professional groups). Eight stakeholders commented that the use of a phased approach to the case definitions (defined by timing of symptoms) was misleading or wrong and provided explanations of their opinion. Three stakeholders suggested use of a phased definition of disease but with the timings of the phases changed. Three stakeholders requested the removal of the term "Long COVID" from the definitions.	The panel noted both the support and criticisms of the case definitions used and discussed the purpose for establishing these. The aim was to reduce the existing confusion about how to define the disease for clinical guidance in the absence of an agreed definition. The panel recognised the significant progress made by patient groups using the term 'long COVID' and the familiarity of the term for affected individuals and agreed that it should be acknowledged in the guideline. However, to facilitate diagnostic coding, service allocation and monitoring and surveillance of clinical activities with granularity across the wide time range where individuals may be affected, they preferred the additional information that was linked to the case definition terms presented in the guideline. They agreed that the term 'long COVID' should be used in patient materials associated with the guideline to make these as

	Three stakeholders requested reference to CFS/ME in the case definitions in a range of different ways. Other comments were raised by small numbers of stakeholders, including • Emphasis on PCR test result being unimportant for clinical management • Request for more detail/specificity in case definitions – specifically, a list of signs and symptoms as the case definition hinged on this • Special circumstances – patients symptomatic but testing negative • Special circumstances - patients within critical care who have been admitted in an acute episode and remain in critical care for over 12 weeks.	accessible as possible and reflect the value of this term to the population with long-term symptoms. Regarding the timing of the case definition phases, the panel agreed that while symptoms may vary, fluctuate in intensity and severity, or recur, the definitions did not necessarily imply that there was a difference in symptoms between the different phases. They noted that, for most people with acute COVID-19, in general symptoms resolve in a linear fashion, with many people recovering after 2-4 weeks, and noted evidence that the majority of people who were still symptomatic at 4 weeks recover by week 12. It was recognised that a sizeable minority of individuals may continue to experience symptoms at 12 weeks, and this was also highlighted as a specific phase of the condition during which care can be provided at the appropriate level, acknowledging that this might change for the individual over time. The panel noted that while fatigue and brain fog were potential longer-term symptoms of COVID-19 in some people, these symptoms were always present in chronic fatigue syndrome / myalgic encephalomyelitis. Moreover, as a number of conditions also share these symptoms, it would not be appropriate to draw direct comparisons between these conditions for the purpose of setting case definitions. The panel agreed that, because of the limited availability of testing in the first wave the result of a test for SARS-CoV-2 was not relevant to the diagnosis. Therefore further text has been added to the section on 'Identifying people with

		ongoing symptomatic COVID-19 or post-COVID-19 syndrome', to clarify that the recommendations apply irrespective of a positive or negative COVID-19 test result. There is also a recommendation in the section on 'Investigations and referral' to emphasise that people should not be excluded from referral to a multidisciplinary assessment service or for further investigations on the basis of absence of a positive SARS-CoV-2 test. The panel did not agree for the need to include this information in the case definition. The panel discussed that the full range of possible clinical presentations had not yet been mapped systematically and were concerned at providing a list of symptoms in a national guideline, because it could potentially miss some. They agreed to include a table of most commonly reported symptoms, in order to raise awareness, but to emphasise that this was neither comprehensive nor definitive.
General	[53 comments] Some stakeholders requested clarification of roles and responsibilities between primary and secondary care, and more detail for MDTs, including composition. This included the suggestion for more detail of neurology and paediatric components in the MDT clinic. A link to the written information resources was requested (see 1.1).	The clarification of settings where certain actions should happen was considered by the panel and text has been added to the start of all sections to identify this. Please see response to recommendation 8.2 for panel decision on MDT. No link to resources has been provided, as information available will vary according to local commissioning arrangements. The panel agreed that a list of common symptoms of would be useful and this has been added to

		the guideline. New text for the assessment of carers' and families' needs was not specifically added to this recommendation as the panel considered that the term 'holistic assessment' references the need to do this.
	Concern was expressed about the lack of advice for assessment of carer's and family needs as part of holistic assessment.	
	Potential challenges of implementing shared decision making and holistic assessments were raised by 1 stakeholder.	These challenges were noted by the panel, but it was felt that recommendation 1.2 provided links to further guidance to support health and care professionals in shared decision making. Moroever, the guideline will make reference to the forthcoming NICE guideline on shared decision making once this is published.
	The need to embed experiences of older people and children was highlighted by 1 stakeholder to expand this section.	Recommendations 1.6, 2.8, 5.7 and 5.8 specifically address issues around diagnosing and supporting children and older people.
	Two stakeholders suggested advice on infectivity post-acute phase through antibody testing.	This is not in the scope of the guideline and therefore no change was made.
	One stakeholder expressed concern of over emphasis on mental health and the risk of misdiagnosis of anxiety.	The panel considered that there needed to be a holistic view of the long-term effects of COVID and that the balance of emphasis on mental and physical health was appropriate.

	One stakeholder suggested that indirect evidence from SARS/MERS be included for extrapolation where evidence is lacking and suggested linking to British Psychological Society guidance. One stakeholder suggested the need for repeated investigations, to allow for relapsing or recurring symptoms. One stakeholder suggested that more detail be included on the content of the rehabilitation prescription to allow ease of use between systems and some consistency in approach e.g. with the trauma rehabilitation guideline. One stakeholder highlighted the absence of coding in the guideline for positive or negative test results to inform other recommendations e.g. investigation of risk factors, or for further research. 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 (see comment 15). Some stakeholders commented that they would like to see a list of the most common symptoms in the guideline. There were also comments on the lack of information about symptoms worsening/relapsing.	Indirect evidence was not used for this guideline for any review question, due to the volume of evidence and time constraints. No change was made to recommend repeated tests, but the fluctuating nature of symptoms is noted in several places in guideline recommendations and rationales. Repeated tests are subject to professional judgement for individual patients. Detail has been added to recommendation 5.5 and the rationale which outlines what the rehabilitation prescription should contain. This is beyond the scope of the guideline. The scope outlines that the population includes people irrespective of whether they have had a positive or negative PCR, antibody or antigen test). The panel discussed whether this should be added and considered that consideration of differential diagnoses was accounted for in recommendations in section 2 and 3 and nothing specific about ME/ CFS needed to be added to the guideline. The panel discussed and agreed that a list of common symptoms should be added to the guideline.

	Whilst stakeholders were supportive of MDT clinical many were questioning the feasibility of these (see comments 18 and 25). One stakeholder requested a list of tests that GPs should carry out (see comment 4) One stakeholder commented that epidemiology and demographics were missing from the guideline as well as recommendations on diet and nutrition. One stakeholder noted that there are no recommendations for the use of assessment and/or outcome measures to record symptom progression and final outcome. One stakeholder queried how organ pathology after COVID-19 would be managed. For example, myocarditis. Would this be considered an alternative diagnosis as described in the case definition?	The panel acknowledged the issues of feasibility and added (if available) to rec 3.10. This has been added in recommendation 3.4 Epidemiology and demographics were not in the scope of this guidance. The panel agreed that dietetics would be a potential expertise needed, dependent on symptoms, and included dietetics in the expertise that might be needed in a wider team in the rationale for recommendation 8.2. Specific assessment and outcome measures of symptom progression were not included in the guideline due to a lack of evidence. However, any new evidence in this area will be monitored for potential impact on the guideline. This was not in the scope of the guideline. As outlined in the scope, where there are clearly defined care pathways for end-organ damage, including myocarditis these should be followed. The panel discussed the NASA lean test and decided that it should not be included. The panel considered that adequate tests for postural symptoms is covered in recommendation 3.6. The patient experience evidence described how some people were not offered tests and other people were

	One stakeholder suggested that the exercise tolerance tests should be extended beyond respiratory symptoms and include screening or orthostatic intolerance e.g. NASA lean test. One stakeholder commented on the need for accurate COVID-19 diagnosis. “In order both better to understand post Covid 19 disease and provide appropriate care for patients with this pathology a diagnosis of viral infection is required.”	refused a referral by healthcare professionals because they did not have a positive SARS CoV 2 test result. Many people who had acute COVID 19 were not tested, particularly earlier in the pandemic. The panel were clear that access to services should not be restricted by the need for a positive SARS CoV 2 test (PCR, antigen or antibody) as reflected in recommendation 3.1.
1.1	[29 comments]	
	One stakeholder suggested renaming this section to: "Identifying people with new or ongoing symptoms after acute Covid-19". Rationale: we cannot identify people with anything specific until the assessment is done, which is covered in Section 2.	The panel considered that the title of this section was appropriate and did not make any changes.
	A number of responses noted that this recommendation related to people who had already had COVID-related contact with health services, and queried how those who had not, would be reached and informed. Stakeholders suggested rewording to clarify meaning of ‘people who had contact with healthcare services...’: “Anyone who attends at any time stating that they have had or think that they have had (Covid-19) infection should be given advice and written information (as stated).”	The panel acknowledged that this recommendation excluded those people who had not had contact with healthcare services and so removed this statement from the recommendation to make it more inclusive of all people who have had suspected or confirmed acute COVID-19
	There was a view that more information relating to the new or continuing symptoms that may be of concern would be helpful.	The panel agreed that a list of symptoms would be useful and have added this information to the guideline.
	More detail was also asked for in relation to which healthcare professionals would be supplying information to patients and at what stage in their	The panel agreed that more detail about the settings in which healthcare professionals would carry this out would

	patient journey. Possible resources that could be highlighted were suggested.	be helpful and so added this to the start of each section of the guideline.
	Given the lack of evidence at this stage, it was suggested that the current uncertainty around symptoms and disease recovery should be alluded to.	The guideline landing page will include details of the uncertainty behind the evidence and the rationales explain where the panel used its expertise or the best available evidence.
	Stakeholders suggested that that the recommendation may be reworded to say that, "...any new or worsening of existing symptoms may trigger a review."	The panel amended the recommendation to include worsening symptoms.
	A link to the written information was requested for users to download and use as a resource for patients.	The panel added a list of possible symptoms, and added these to the guideline, but they did not add a link to written information, as this would vary according to the local area.
	Stakeholders suggested adding to the first bullet point: ['-what to expect during their recovery'] "..., and advice on how to self-manage during recovery (e.g. www.yourcovidrecovery.nhs.uk)"	The panel agreed and added this to the recommendation. The Your COVID recovery website is included in the rationale as an example of support.
	Stakeholder suggested rewording to clarify ambiguity around being 'reassessed', e.g. people could think it means reassessment of whether they had Covid-19 or a different condition, or reassessment of long Covid diagnosis. [I think It actually means that the patient needs further healthcare assessment...]	The panel agreed and amended the recommendation to reflect that this meant symptoms to look out for that mean that the person should contact their healthcare professional.
	-Stakeholder suggested that the recommendation may need further clarification around who is doing this reassessment (e.g. patients and primary care, or others also); and when/what is the trigger (e.g. additional symptoms, escalation of patient concerns, etc.)	Please see responses above re: rewording of recommendations to clarify who should be doing the reassessment and triggers for reassessment.

1.2	[11 comments] Most comments provided by stakeholders related to encouraging availability of multiple formats and languages to suit people with learning difficulties, ethnic minorities, etc. Two stakeholders proposed making a clear recommendation on providing information in easily digestible formats for people experiencing symptoms of prolonged COVID-19 or post-COVID syndrome, particularly those experiencing fatigue or brain fog. Two stakeholders suggested specifically referencing the 'relevant national guidance' in the recommendation.	No action – comments support recommendation. Information was added to the rationale which detailed that the format of information should be considered for people experiencing fatigue or brain fog. Links to the relevant national guidance were added to the recommendation.
1.3	[20 comments] Stakeholders requested clarification in the text around the rationale between the timings of 4-12 weeks and 12+ weeks. They suggested that it might be clearer to say that symptoms maybe ongoing or develop over time and post-COVID can be diagnosed after 4 weeks. Stakeholders requested a definition of ongoing symptoms, for the inclusion of a list of symptoms and definition of what symptoms after 12 weeks are used to define post-Covid. A stakeholder queried the presentation of symptoms and how they compare to ME/CFS where symptoms occur after a viral syndrome	This recommendation was edited and amended based on stakeholder feedback so that it is clearer. A list of symptoms has been added to the guideline. No further information was added to the recommendation regarding ME/ CFS as the panel considered that this was already accounted for in recommendations in section 2 and 3 which relate to considering differential diagnoses as well as post-COVID-19 syndrome.
1.4	[29 comments] Several stakeholders queried the implication in the recommendation that patients would be pro-actively engaged and the mechanism,	The recommendation has been edited to clarify that this recommendation is about offering an initial consultation to

	resource/workload, and clinical implications (and potential harms re medicalisation) of this. There was debate within the comments as to whether there should be any mention of using a screening questionnaire, if none are validated. Some stakeholders wished specific questionnaires to be mentioned as examples. There were several queries as to why only remote consultation should be offered and how this may adversely impact on some groups without access to technology or privacy. However, there was some support for remote or in-person consultation, depending on circumstances. There were also queries about who should be doing this – not assistant grades.	assess whether the person may have ongoing symptomatic COVID-19 or post-COVID-19 syndrome Please see the responses to recommendation 1.5 for details about changes made regarding the screening questionnaire. Recommendation 1.4 was amended to say that a shared decision should be reached about whether phone, video or in-person consultation is most appropriate for the person. No change has been made with regards to this point; local service should identify health care professionals with the appropriate competencies to undertake these tasks.
1.5	[16 comments] In general, comments concerned a need for greater clarity indicating why a screening questionnaire could be useful as part of a screening process - and what else that process might involve, e.g. a full physical and psychological history, exploring every system in the body, to ensure all symptoms are identified. One stakeholder suggested explicitly noting that questionnaires should not be the sole method as they are not validated. One comment suggested avoiding the term 'assessing' within this screening process recommendation.	This recommendation has been amended based on stakeholder feedback to recognise that screening questionnaires can be useful if used in conjunction with a clinical assessment, because questionnaires alone may not capture all of the symptoms. It has been noted in the rationale that currently no questionnaires are validated. However, the panel noted that they were useful and decided that it was right that their use (alongside clinical assessment) be highlighted in the recommendations. The word 'assessing' has been removed from this recommendation.

1.6	[16 comments] There was concern about specifying particular age groups in which fewer common symptoms may be found and that this was inappropriate as varied symptoms could be found at any age. More detail of possible symptoms was requested. It was also noted that there was a need to ensure consideration of potential gender biases, to make clear that people may have mild initial symptoms and also that in some cases it may be necessary to involve another family member or carer in assessing symptoms. Lastly, 1 response highlighted that more clarity is needed throughout section 1 on the use of a screening questionnaire in assessments	The panel discussed and agreed that the wording of the recommendation should be changed, so that it highlighted that 'some' people (including children and older people) may not have the most commonly reported symptoms after acute COVID-19. A list of symptoms has been added to the guideline. Equalities issues were discussed by the panel and details of how they have been addressed are recorded in the equalities impact assessment, which was published alongside the guideline. The recommendations on the use of screening questionnaires in consultations has been clarified and details of the amendments can be found in the responses for recommendations 1.4 and 1.5 above.
1.7	[18 comments] Comments identified some confusion between screening process and screening tools. Needs rewording. A stakeholder highlighted that offering choice of in-person or remote consultation depended on patient circumstances in relation to access to technology and privacy. They suggested that the recommendation could be reworded to encompass/acknowledge patient need and patient preference.	The use of the term 'screening' has been reviewed throughout this section and amended accordingly to make clear that the intention is to cover screening tools. This recommendation has been amended and expanded to reflect that this should be a shared decision, and should take into account the persons symptoms, whether they need investigating in person and whether they may need urgent referral to an appropriate service.

	Two stakeholders asked whether their specific clinical situations/red flags for differential diagnoses/ or other aspects which should trigger full assessment could be recommended. One comment suggested an opportunity to combine 1.4 to 1.7 possibly resolving the queries highlighted at 1.4 around the implied pro-active identification.	The panel agreed with stakeholders and added that the healthcare professional should 'Take into account whether they may have symptoms that need investigating in person or require urgent referral to an appropriate service' 1.4 and 1.7 have not been combined, but all recommendations in this section have been amended for clarity and to take into account stakeholder comments.
1.8	[26 comments] There were multiple comments around proactively contacting vulnerable groups. Stakeholders asked who is going to contact people and asserted that it is unrealistic to expect GPs to do this, as they don't have the manpower. They also highlighted that GPs may not know who to follow up and people may not seek help or inform their GP.	This recommendation has been amended. The panel discussed (and some stakeholders commented) that mandating proactive follow up of people with a positive COVID-19 test or who self-isolated was not pragmatic and primary care does not have the resource to support this. Therefore, this bullet point was removed. The panel agreed that there was still a need for vulnerable or high-risk groups to be contacted by primary care and so made a new recommendation (1.9) which directs people to 'consider follow up by primary care or community services for people who are vulnerable or high-risk who have self-managed in the community after suspected or confirmed acute COVID-19'
	The term underserved or vulnerable was considered in one comment was considered to be discriminatory against people who did not fall into those groups?	The evidence and panel expertise suggested that it was appropriate to highlight underserved and vulnerable groups as having potential difficulties with accessing services.
	There was a comment around carers of people in vulnerable groups also being followed up.	The focus of this guideline is people who have had are suspected to have ongoing symptomatic COVID-19 or post-COVID-19 syndrome, therefore the panel agreed it was not

	Other comments from stakeholders related to the definition of underserved or vulnerable groups – who are they, do they include prison population, how is this to be done (consider hard to reach groups such as homeless)	appropriate to have a recommendation on the follow- up of carers of people in vulnerable groups. Comments relating to equalities are noted in the equalities impact assessment and the panel considered the impact of the guidance on all equalities issues.
2.1	[21 comments] There were several comments about lack of clarity on this recommendation – in particular who should do it, where and which people should be assessed? One stakeholder commented that a 'focussed clinical history' is the wrong way of carrying out this assessment'. There were several comments asking for more detail on investigations, including what should be done in primary care, more detail on what investigations should be done before referral and timing of them after acute COVID. It was also suggested that the guideline should link to other guidance (e.g. NHSE). There were varying stakeholder views on the use of the terms psychological and psychiatric. Some stakeholders welcomed inclusion, 2 thought the recommendation overemphasised PCS as a psychological issue, 1 suggested psychological may be a better term and another suggested 'mental health'. There was a suggestion to add red flags here, comments also suggested addition of behavioural assessment, validated screening tools, chemosensory dysfunction and adding work to functional abilities.	A short section of text has been added to the start of each section to highlight the population and settings that the guideline recommendations relate to. The panel agreed and focussed clinical history was changed to 'comprehensive clinical history' The panel agreed that more detail could be added on what tests could be carried out in primary care and added this detail in a new recommendation (3.4). Detail has also been added at the start of the section on investigations and referral about what settings these tests should be carried out in. Where appropriate, links to other guidance have been added to the rationale. The panel discussed that it was appropriate to have psychiatric and psychological listed, because people can present with these symptoms. The panel agreed that they did not want to over-emphasise a psychological issue but concluded that a holistic approach was needed for assessment of a person who may have post-COVID-19 syndrome. No change was made. The panel agreed not to add red flags to this recommendation, as these are highlighted in other recommendations. No other suggestions were added to

		this recommendation, because details of assessments are provided in other recommendations in this section and the panel agreed it was not appropriate to add details here.
2.2	[15 comments] There was a request from one stakeholder to add details on what was needed for diagnosis (clinical only), another stakeholder stated did we want to use antibodies to diagnose condition.	The panel discussed and agreed that a list of symptoms would be included in the guideline, which may aid diagnosis. A specific list of symptoms was added to the guideline.
	One stakeholder said that there should be specific mention of paediatric multi-inflammatory syndrome here.	The panel agreed that paediatric multi-inflammatory syndrome should be added to the guideline and was added to recommendation 3.1
	Stakeholders suggested the addition of other things to be tested (anosmia etc).	Other symptoms to be tested for were not added here, as the panel agreed that this recommendation was focussed on the overarching aspects that the clinical history should focus on.
	2 stakeholders noted that past and present medical history should be included here, and another commented that help seeking, and health care behaviours should be noted.	The panel agreed and ‘history of other health conditions’ was added to the recommendation. However, the panel did not think that help-seeking and health care behaviours should be included here.
	2 stakeholders commented that a recommendation is needed around taking a systemic history to identify a potential non-COVID cause.	The panel discussed the need to take a thorough history to establish if the cause of illness was not COVID-19 related, therefore they amended recommendation 2.1 and 2.2 to state that a ‘comprehensive clinical history’ should be taken.

	Other comments noted that this underemphasises the physical aspects of the illness. The stakeholders also commented that reference to other conditions experienced by people with Long COVID should be noted.	The panel noted that symptoms can be physical, psychological or psychiatric and the panel wanted to ensure that a holistic approach was taken to assessment and care. The panel noted that people may have pre-existing conditions but may also have conditions as a consequence of COVID, both of which should be managed optimally.
2.3	[16 comments] Overall comments for this recommendation suggested it was well received, with one person commenting this was good practice and could be shortened. There were requests from 3 stakeholders that caring responsibilities should be added to this list, other suggestions include sleep patterns, relationships and others. It was noted by 1 stakeholder that details of 'how this impact on symptoms' should be added. This was also mentioned by another stakeholder who viewed that this recommendation was more interested in acute COVID symptoms rather than focussing on current, ongoing symptomatic or PCS symptoms.	The panel agreed that the list within these recommendations were examples of what could be discussed and decided not to add more aspects for discussion to the list. The recommendation was re-worded to clarify that this was about the effects of ongoing symptomatic COVID-19 or post-COVID-19 syndrome on the person's life.
2.4	[11 comments] Comments for this recommendation suggested it was well received, with one person commenting that this could be patronising for clinicians though they understood it was valuable. There were suggestions for various issues to be added to the list including relationships, work, loneliness, costs. One person suggested that it should read 'beliefs and experiences' (BPS)	The panel agreed that no changes were required for this recommendation, as the wording of the recommendation was viewed as broad enough to encompass the issues raised.
2.5	[10 comments] There was broad support for this recommendation, with 3 stakeholders commenting that the recommendation needed clarity on who should do this.	This recommendation was reworded to clarify the meaning (now recommendation 2.6). The panel concluded that it was not necessary to make reference to particular roles that might support for specific needs as the recommendation was intended to emphasise

	1 stakeholder suggested adding specific support from SALT for people with communication issues	the role that family members or carers could play during consultations.
2.6	[11 comments] There was a general view that a specific list of symptoms (or link to) would greatly improve this recommendation and make it more useful. 1 stakeholder suggested asking person explicitly about symptoms. 1 stakeholder thought that the guideline should distinguish between fluctuating and relapse/ remitting, this ignores the fluctuating symptoms in the acute phase.	The panel agreed and a list of common symptoms was included in the published guideline. The panel noted that recommendation 2.3 includes the fluctuating nature of symptoms and agreed that this was sufficient, so did not add information about relapsing/ remitting symptoms here. Acute COVID-19 is not in the scope of this guideline.
2.7	[16 comments] There were several comments on using the term post exertional malaise instead of post-exercise malaise. Some stakeholders noted that many symptoms overlap with CFS/ME. There were 2 suggestions that ZOE app data should not be used to determine the likelihood of developing post-COVID syndrome. There was one suggestion that the list of symptoms should be easier to read and come earlier for ease of reference There was one suggestion that the guideline should state likelihood of going on to develop CFS/ME and that reference should be made to a generic post-viral syndrome rather than PCS, as we don't know what PCS is yet. One stakeholder commented that the likely length of symptoms would be useful to list here, so clinicians know what to expect.	The panel discussed stakeholder comments and agreed to remove this recommendation, as they agreed there is currently not enough known to state what makes someone more likely to develop post-COVID-19 syndrome. A list of symptoms has been included in the guideline and referred to at the relevant recommendations. 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 panel agreed that they could not add the likely length of time that symptoms last because this is a new illness with an immature evidence base.
2.8	[11 comments] There was one comment that inconsistency of language between 2.7 and 2.8 is confusing.	Recommendation edited to clarify population.

	There were 4 queries regarding what else should be relied upon if not clusters of syndromes alone. One stakeholder noted that many clinicians still believe severity of long COVID is associated with severity of acute COVID.	The panel agreed with the stakeholder comments. The wording of this recommendation (now recommendation 2.7) has been amended in response to the stakeholder comments to clarify meaning.
2.9	[10 comments] One stakeholder noted inconsistency of language between 2.8 and 2.9. One stakeholder commented that we should be aware of other causes of decline and not attribute all too long COVID. Another stakeholder noted that that people will be likely to attribute decline to effects of lockdown per se, rather than atypical presentation of COVID. 2 stakeholders commented that this recommendation was too broad to be useful, and that common causes for decline still need to be assessed. 1 stakeholder noted the association of intubation and tracheostomy with eating and swallowing issues and asserted that the relevant professionals should be involved in care.	The panel agreed with stakeholder comments that post-COVID-19 syndrome should be a part of the differential diagnosis of an older person who is presenting with these features (deconditioning, worsening frailty etc) and agreed to change the wording of the recommendation to reflect this. No change was made to the recommendation based on this comment because it was not directly relevant to the recommendation.
2.10	[18 comments] The majority of stakeholders requested an example of a validated tool for use One stakeholder reported that 'being lost for words' is common in Long COVID One stakeholder noted that there are a range of cognitive assessment tools, but none are specific to this situation. They suggested that a rehabilitation specialist would be able to specify which is the most appropriate assessment tool and highlighted that family members are often the first to spot changes and their views should be sought. One stakeholder commented that cognitive tests often don't pick up these changes because symptoms fluctuate.	The panel discussed the stakeholders request for an example of a validated tool to assess cognitive symptoms, however they decided not add examples. This is because they concluded that the most appropriate tool will vary depending on what setting the person being assessed is in and the type of assessment required. The panel agreed that it was not appropriate to state what happens if a score indicated the need for onward referral, because it would depend on the person's holistic needs.

	One person commented that a test for other psychological difficulties should also be undertaken. They cautioned that not all tests will pick up changes and that passing a cognitive test should not prevent an onward referral for people if the clinical history indicates that there have been cognitive changes. One person questioned using a cognitive test based on 'new cognitive symptoms' and that instead any further action should be based on comprehensive clinical history	The panel agreed that any assessment tool results should be taken into account along with the clinical history (and physical and psychological assessment) and should not be used in isolation.
Section 3	**<u>General comments about section 3:</u>** There were a number of general comments indicating that clarity was needed on who a patient is referred to, where services sit, and which specialities drive care management. It was highlighted that clinicians need a steer as to what needs doing in what patient. -One comment indicated a need for a general recommendation for understanding and interpreting findings and the onward referral pathway. Stakeholders commented that guidance on when a person should be referred from primary care would be useful It was highlighted that rehabilitation referral is important and should be mentioned at the start of the section. One stakeholder commented that it is unclear what role Long COVID clinics play.	The panel agreed with this comment and added text at the start of each section to state which settings the recommendations apply. It is beyond the scope of this guideline to provide evidence on understanding and interpreting findings; therefore no information was added here. The panel considered that options for onward referral pathways are outlined in the guidance. Rehabilitation referral is mentioned later in this section of the guideline and was not moved as the panel agreed it was at the right place in the guideline. This guidance covers the 4 nations and therefore the panel agreed not to make specific reference or provide further details of the Long COVID clinics, which currently only exist in England.
3.1	[18 comments] One stakeholder commented that symptoms should be changed to signs as all of these are signs. 4 stakeholders asked for more aspects to be listed as red flag examples (neurological emergencies, anaphylaxis and others).	No change made because the panel agreed that the intention is both symptoms and signs. No other conditions were listed as signs or symptoms that could be an acute or life-threatening complication, because

	Another stakeholder requested a link to where the reader can access detail on PMIS. One stakeholder wanted clarification on which exercise tests should be relied upon for the 'desaturation on exercise' statement. One stakeholder stated that it should be severe hypoxaemia, not just hypoxaemia. One person suggested a change of wording to 'refer patients with ongoing or new symptoms following acute COVID', as this doesn't presuppose a diagnosis.	this is a list of examples. Wording was added that these signs and symptoms 'included, but were not limited to', in order to emphasise that these are examples only and not an exhaustive list. No link was added about PMIS, as clinicians should access locally approved sources of information. The panel agreed that this should not be changed because desaturation on exercise refers to people who may experience symptoms when carrying out usual daily activities rather than specific clinical tests. Amended to severe hypoxaemia as per stakeholder comment. No change was made as the panel agreed that the current wording was accurate.
3.2	[13 comments] There were some comments around why there was an emphasis on mental health issues when fatigue is more common than anxiety. There was concern from 1 stakeholder that management should be appropriate for both physical symptoms and psychiatric/ psychological (concern around emphasis on psychological). One stakeholder suggested that it would be better to move tests for physical issues (rec 3.3 - 3.6).	The panel agreed to reorder the recommendations, so that physical examinations came first, in order not to emphasise mental health issues.

	One stakeholder noted that this applies to all people – and queried whether the risk of psychiatric issues is higher in this population. 2 stakeholders commented on commissioning of these services and availability given current issues accessing services.	The panel considered that referral for psychiatric assessment is usual care for people with severe psychiatric symptoms or were at risk of self-harm or suicide and noted that in their experience this was not a common presentation in people experiencing long-term effects of COVID-19.
3.3	[32 comments] It was suggested that reference to primary care be expanded, including referral criteria to secondary care and more detail on lung function tests given. Several stakeholders indicated these are not being done in primary care due to being aerosol generating and they are likely to be delayed beyond 12 weeks in secondary care. It was suggested that a respiratory physiologist led service would be needed in primary care for lung function tests. One stakeholder suggested the alternative testing of oxygen saturation on air with onward referral to respiratory medicine for those with significant desaturation. Several stakeholders suggested linking to related guidance, either related NICE guidelines on testing, or British Thoracic Society guidance on resumption of lung function testing. Two stakeholders indicated that time points should be stated for when tests are to be completed, 1 suggesting an accompanying visual aid. One stakeholder indicated that psychophysical testing is necessary to confirm diagnosis. Several stakeholders suggested inclusion of various additional tests, including an additional bullet for imaging, as patients are being diagnosed with myocarditis, and inclusion of neurological investigations. Conversely, 1	Text was added to the start of section 3, which states that these recommendations are for ‘people having initial investigations in primary care or community services. The panel agreed that lung function tests should not be carried out in primary care and so removed this from the recommendation. They also agreed that more guidance was needed for primary care, and so added another recommendation (3.3) about undertaking appropriate investigations if alternative diagnoses are suspected. The reference to lung function tests was removed from the recommendations and so no guidance was linked to. The panel did not think that time points for undertaking tests should be added but agreed that by adding detail about the setting in which these should be carried out

	stakeholder suggested removing example tests to avoid raising patient expectations for these tests, and to emphasise the need to tailor tests to the person's needs. One stakeholder advised inclusion of advice for expected results of blood tests in ongoing COVID, or whether the tests should be normal, to reduce unnecessary risks. One stakeholder suggested rewording 'depending on setting' to avoid implication of settings determining tests instead of clinical presentation.	would provide some indication to healthcare professionals about where in the pathway these would occur. The panel discussed the list of tests and amended them to reflect common tests that would also be undertaken when considering differential diagnoses to make the tests undertaken as useful as possible when considering whether a person may have post-COVID-19 syndrome or another diagnosis. The panel did not add details of expected results for blood tests as this will depend on the individual patient. The wording 'depending on setting' has been removed from the recommendation.
3.4	[21 comments] There were multiple comments around the usefulness of the tests mentioned and challenges with the primary care setting when many appointments are remote. Stakeholders queried who would conduct them and highlighted the need for education and training around the tests within primary care. Two stakeholders suggested that the tests be carried out in secondary care. 1 stakeholder expressed concern of risks of exacerbation of symptoms as a result of exercise testing and risk of cardiac arrhythmias indicating the need for ECG monitoring during the test. 1 stakeholder stated that patients with physical impairments would not be able to carry out this test.	The panel discussed this comment and agreed that the 1-minute sit to stand test was useful and should stay in the guideline. The panel discussed the fact that the rationale linked to a document which provided guidance on how to carry out a sit to stand test safely, and also made reference to sharing skills between specialist care and primary care. The panel felt that these aspects alleviated any barrier to the test being carried out in primary care. The panel went on to discuss that previous recommendations emphasise a shared decision about whether appointments should be in person or virtual and this should, in part, be based on the persons symptoms and any tests required. The panel discussed that you would only undertake this test if it was safe for the person to do so and amended the recommendation to say 'if appropriate' to take this into account.

	There was a query around ME/CFS patients who cannot tolerate exercise and should not be pushed beyond their limits. 1 stakeholder suggested inclusion of other elements of the Senior Fitness test or the 2- or 6-minute walking test, with benefits of minimal experience and training by the assessor. Several stakeholders raised questions around what the evidence base for exercise tests is in comparison with asking people to assess their own tolerance. 2 stakeholders expressed concern around the absence of advice for oxygen saturation measurement during the exercise test and why blood pressure monitoring is mentioned without any rationale.	The panel discussed these tests but did not consider that they needed adding here because their value in assessing people who may have long-term effects of COVID is unclear. No evidence was identified for comparing exercise tests to people assessing their own exercise tolerance and so no recommendation was made on this. The panel agreed with the stakeholder and added oxygen saturation to the recommendation and removed the reference to blood pressure monitoring.
3.5	[12 comments] There were requests for parameters and protocols for the test mentioned. 1 stakeholder suggested postural symptoms/giddiness may follow weight loss during the acute illness which reduces the requirement for BP medication and this needs to be made clear in the recommendation. There was a suggestion to use the term orthostatic intolerance rather than postural symptoms There were several queries around who would conduct the tests as unrealistic to expect it could take place within a GP consultation	The panel discussed the stakeholder comments and considered that the suitable protocols for this test were included in the Royal College of Physicians' brief guide on measuring lying and standing blood pressure and so linked to this in the rationale for the recommendation. The panel considered that this level of detail was not required within the guideline as this is not specific to the population of this guideline and should form part of the holistic assessment. No change was made to the term 'postural symptoms', as the panel considered that this was accurate.

		The panel added text at the start of this section to clarify that these tests would be carried out in primary care or community services.
3.6	[14 comments] Various stakeholders were looking for greater clarity around positioning of x-rays within the diagnostic pathway; in particular what conditions it is being used to investigate and what the findings should lead to. It was suggested that an accompanying diagnostic algorithm should be prepared. Some stakeholders queried whether x-rays should be undertaken earlier than 12 weeks.	No diagnostic algorithm is being published alongside the guideline. The recommendation has been amended to provide greater clarity on the timing and purpose of chest X-ray. The recommendation states that chest X-ray should be undertaken by 12 weeks after acute COVID-19.
3.7	[21 comments] Comments were received which suggested: • Addition of social prescribing and occupational therapy in primary care • Screening for mental health symptoms or psychiatric symptoms by an expert • Issue of current long waiting times for psychological services • Should recommendation include advocating exercise or use of antidepressants? • Addition of IAPT and cognitive assessments in primary care • Addition of text to indicate that patients who are upset or worried due to their illness are not necessarily requiring referral to psychological services.	The panel considered the various suggestions but decided that it was not appropriate to add any further information here on commissioning issues, who should be doing the screening or the use of antidepressants. IAPT was not added, because this is specific to England and this guideline covers the 4 nations. Cognitive assessments are already covered in a separate recommendation (2.9). Detail on patients may be worried or upset due to their illness, not requiring referral is detailed in the rationale of the guideline.

3.8	[13 comments] There was strong support for the recommendation. Almost all stakeholders suggested it should come earlier in the document, e.g. ahead of 3.3 on ruling out underlying diagnoses. One comment was that it should be an equal consideration, rather than 'do not discount'. Two suggestions that this recommendation could incorporate specific red flags for other important alternative diagnoses e.g. DVT/PE	The panel agreed that this recommendation should come earlier, and it was moved to 3.2. The panel also discussed that the wording should be changed, so that it was an equal consideration. Detail was also added to the recommendation that clinicians should carry out tests and investigations that rule out acute or life-threatening complications (red flags).
3.9	[18 comments] The majority of comments suggested re-wording the text to ensure that people without a positive SARS-CoV-2 test are not excluded from referral, further investigations or specialist input. Some comments concerned the lack of rehabilitation services being a barrier to implementation.	The panel agreed that this recommendation (now recommendation 3.11) should be reworded to clarify that people who would benefit from rehabilitation or specialist care should be referred irrespective of whether they had a positive SARS-CoV-2 test (PCR, antigen or antibody). The panel acknowledged the potential issues around the lack of rehabilitation services being a barrier to implementation but concluded that the recommendations were best practice and should be aimed for.
4.1	[33 comments] One stakeholder queried whether the holistic assessment referenced was the same as mentioned in recommendation 2.1. They also queried who was responsible for this assessment. One stakeholder commented on the need to include families and carers in the holistic assessment particularly for those with cognitive deficits.	The clarification of settings where certain actions should happen was considered by the panel and text has been added to the start of all sections to identify this The panel considered this and agreed to amend the recommendation to say "After the holistic assessment, use shared decision making to discuss and agree with the person (and their family or carers, if appropriate) …"

	Stakeholders suggested that specific information on self-management was required. They requested clarity on what it involves, what is meant by 'supported' self-management' and who will provide support where necessary. There were suggestions to signpost to digital resources for self-management and add information on peer support. One stakeholder suggested offering guidance on resting, pacing and diet when offering advice on self-management.	The term supported self- management is used in this guidance to mean the same as set out in NHSE/I documentation (https://www.england.nhs.uk/personalisedcare/supported-self-management/). The panel considered that the specific information around self-management would be covered under the Self-management and supported self-management section of the guideline. To make this clear, recommendation 4.1 now cross refers to this section. However, recommendations on resting, pacing and diet could not be added as the panel felt that they did not have sufficient evidence to inform this.
	One stakeholder suggested that there should be more detail on what should not be offered to patients such as graded exercise therapy for people experiencing post-exertional malaise. They suggested that more advice on when patients can stop treatment/management at any point without affecting support would be helpful.	The panel considered stakeholder comments and agreed that more this level of detail for management would be dependent on the individual's needs. This would form part of a rehabilitation prescription, which is covered by recommendation 5.5.
	Stakeholders noted other support services beyond healthcare, including potentially for families/carers also, and including social prescribing, support for population groups experiencing high impact (e.g. women, people from BAME communities), occupational therapy and financial /housing support. They also mentioned partnership working with local VCSE organisations should be included, including their potential support to self-management and to consider the role of occupational health.	These considerations are discussed in the responses to recommendation 5.1.
	One stakeholder suggested that 'diagnosis and treatment' should be added to the recommendation.	The context of this recommendation is after assessment has occurred and covers discussions around management which will include any treatment. Diagnoses discussions are covered in sections 2 and 3 of the guidelines.

	One stakeholder suggested that the wording ‘This should include’ should be replaced by, ‘This could include’, since the recommendation is consensus rather than evidence based. An alternative option could be: ‘Depending on clinical need patients may be managed by primary care practitioners with referral to specialist services as necessary.’ Stakeholders queried whether patients who meet the diagnostic criteria for ME/CFS should be referred to specialist ME/CFS services. One stakeholder queried what the distinction was between multidisciplinary assessment versus specialist. Stakeholders also flagged that integrated services are not available in some areas. Stakeholders queried why a timing of 6 weeks had been used for referral to the integrated multidisciplinary assessment service. It was highlighted that this was contradictory to the 12 weeks definition in the case definition. There was also concern that referral at 6 weeks could overwhelm the system at the detriment of other patients that require	The panel used this wording, because it was considered important to encourage healthcare professionals to offer some level of management for people with new or ongoing symptoms, which was determined by their individual needs. The panel discussed whether this should be added and considered that consideration of differential diagnoses was accounted for in recommendations in section 2 and 3. Based on stakeholder feedback the panel agreed to amend the recommendation to clarify that the advice is to consider “referral to specialist care for specific complications” which is different from the “referral to an integrated multidisciplinary assessment service”. Text was added to the recommendation to clarify that referral would be dependent on local pathways to account for areas without access to an integrated multidisciplinary service. The panel discussed stakeholder comments and agreed that it was best to remove “from 6 weeks” from this recommendation. They also removed mention of “red flags” from this recommendation.

	the service. One stakeholder highlighted the need to list red flags to clarify what constitutes 'serious underlying cause'.	
4.2	*[10 comments]* One stakeholder suggested that this section may be better if the most appropriate lead specialty could be identified. They suggested that there was a need to consider integration of mental health support too. Another stakeholder suggested that impact on 'work' should be mentioned explicitly One stakeholder noted that appropriate level of support is not well defined and suggested signposting to low tiered supportive provision of information in an accessible format. Stakeholders suggested adding to the discussion around co-/multimorbidity, their symptoms, and the need to consider non-clinical needs including the level of financial independence. One stakeholder suggested the inclusion of details on identification of triggers or precipitating factors to support identification of fluctuations in symptoms. There was further suggestion for consideration of post-exertional malaise, due to potential for harm.	Recommendation 4.2 aims to encourage discussions on planning care that consider the overall impact that symptoms are having on a person's life. The panel did not add "work" to the recommendation, because the impact would not be limited to just employment. Details around mental health support is not specifically mentioned in the recommendation as it is included as part of recommendation, 4.1. Section 4 of the guideline aims to provide recommendations on what to consider with regards to support and rehabilitation needs. Discussions around comorbidities would be considered as part of the initial holistic assessment described in recommendation 2.1. Discussion around non-clinical needs is encouraged in recommendation 5.1 on self-management and supported self-management. The panel did not feel that they had sufficient evidence to enable them to recommend specific guidance on identifying precipitating factors for fluctuating symptoms.

		The panel discussed whether this should be added and considered that consideration of differential diagnoses was accounted for in recommendations in section 2 and 3.
4.3	*[13 comments]* There were several comments from stakeholders around needing more information on early referral. They highlighted a discrepancy between referral from 6 weeks (recommendation 4.1) and consideration of early referral (recommendation 4.3). They also highlighted a potential discrepancy with needing to delay referral by up to 12 weeks, based on the case definition, if red flags need to be excluded. Another stakeholder commented that this recommendation was potentially unhelpful considering the lack of current evidence and the impact on resources, given that most symptoms will improve over time. One stakeholder suggested adding "...and/or family (for those unable to make informed decisions about their health or care requirements)". One stakeholder suggested that early referral might need to be considered for all symptoms, not only those requiring MDT rehab. One stakeholder suggested that section 4 should include more on treating symptoms, including any underlying organ pathology. One stakeholder suggested including psychological and/or nutritional support, for chemosensory loss.	The panel considered stakeholder feedback and agreed that recommendation was confusing and decided to remove it from the guideline. Recommendation 4.3 has now been removed following stakeholder feedback, so these changes are no longer required. The panel considered this suggestion and recommendation 4.1 has now been amended to include referral to specialist care for specific complications which will include treating underlying organ pathology. Section 4 of the guideline aims to provide recommendations on what to consider with regards to support and rehabilitation need. Details on management are covered in section 5 of the guideline.

5.1	[33 comments] One stakeholder commented that the recommendation was “too simplistic and not very helpful as the majority of the aspects covered are dictated by common sense and logic, lacking the novelty and detail that someone with long COVID-19 would expect to receive from a healthcare professional”. There appeared to be conflicting comments on the use of Your COVID recovery. Stakeholders in support of its use requested more detail about the rehabilitation approach it uses whereas those not in support of its use highlighted the issue with graded exercise therapy. There were also requests for more online resources to be added to the guideline including RCOT and the forthcoming resources from the British Lung Foundation. There were several comments on the lack of recommendations on managing specific symptoms considering they are discussed in the draft CFS/ME guideline. These stakeholders were particularly concerned with the emphasis on rehabilitation and goal setting. There were several comments highlighting the lack of advice around pacing as opposed to realistic goals. Stakeholders seem to disagree with the use of the phrase “realistic goals” suggesting that this implies people pushing themselves to achieve which may cause harm. Suggestions for amending this wording include “person-centred goals or “expectations”. There were several comments around this recommendation querying what information or advice should be given. Stakeholders wanted to know which	The panel considered the comments on this recommendation but made only minor changes to the wording of the recommendations as they considered the text to be largely appropriate. The changes made were to give advice starting from the initial assessment, and the removal of the link to the NHS website Your Covid Recovery as an example source of online support. The reference to Your COVID recovery was removed from the recommendation and is referred to in the rationale. This is because there are other digital support tools being developed and the panel considered that it would not be appropriate to only list 1 in the recommendations as this could quickly become out of date as more services become available. The panel agreed that the terms used here were appropriate for supporting people with ongoing symptomatic COVID-19 or post-COVID-19 syndrome., highlighting that there was not enough evidence to support parallels to be drawn and also the data that suggested the majority of people in this population recovered by 12 weeks. The panel discussed that if people were suspected to have CFS/ME then those guidelines should be used to guide treatment. As stated, the panel were clear that conclusive parallels could not be drawn, and the panel were satisfied that realistic goals did not mean that people should push themselves and cause harm.

	services should be involved, e.g. occupational health, voluntary sector etc. They also noted that the recommendation advises sharing information on new or continuing symptoms, but as these symptoms are not in the guideline, they query what this information is. Another concern around this recommendation was the need for awareness of accessibility, particularly as the recommendation mentions digital resources and sharing information.	The panel discussed adding more detail to this recommendation with regards to what information or advice should be given but agreed not to add further detail as this would vary depending on the location of services and considered that local services have already developed their own information to share with patients. The panel noted the issue around accessibility, and this is taken account of in the equalities impact assessment. The panel noted that there are printed formats available within Your COVID recovery.
5.2	[9 comments] Several stakeholders suggested that the national guidelines referred to for vitamin D should be hyperlinked. One queried whether the national guidelines refer to black and ethnic minorities and risk of deficiency. Two stakeholders suggested expanding wording to incorporate discussing contraindications and comorbidities with patients. One stakeholder indicated the need to ask patients what non-pharmacological remedies they are using and offering advice on interactions. One stakeholder suggested mention of free vitamin D to the clinically extremely vulnerable, as recently announced.	The panel agreed that the reference to vitamin D should be removed as it was misleading. The panel agreed that no further wording should be added to the recommendation, as this information was not reviewed. The panel removed mention of vitamin D as it was not appropriate here and there is separate guidance on this from a variety of national bodies.

5.3	[18 comments] Several stakeholders suggested linking to the national guidelines, including Faculty of Occupational medicine, on returning to work, 1 also suggested a link to Your COVID Recovery which includes a page on this. Two stakeholders highlighted the need for more detail on accessing occupational health services, with approximately 50% of UK workers having access. The term ‘support’ in the text was considered too broad by several stakeholders, who requested details including which health professional would provide this, and whether it includes issuing fit notes. One stakeholder suggested advice to support people include reasonable adjustments including digital solutions and working from home arrangements. One stakeholder suggested conducting risk assessments for return to work.	The panel agreed that no further detail should be added to this recommendation, because these would vary according to the patient’s needs and locally available services.
5.4	[22 comments] Stakeholders highlighted the need to include evidence on cardiac abnormalities in assessing safety of rehabilitation, including the Coverscan study. Stakeholders queried whether the recommendation was necessary in addition to assessment section earlier in guideline and whether this was additional assessment of patients. They asked whether a link should be made between this recommendation and related recommendations in the assessment and referral section. Stakeholders suggested adding a recommendation around the composition of the rehabilitation MDT including involvement of a rehabilitation clinical expert and speech & language therapy	The panel agreed that no extra detail on assessing safety of rehabilitation was needed, because the recommendation already makes reference to this. The panel considered that this recommendation was required because it pertains to multidisciplinary rehabilitation, rather than multidisciplinary assessment. The composition of the MDT is outlined in recommendation 8.2; a link to that recommendation was added to recommendation 5.4 for ease of cross referencing. Speech and language therapy were not directly mentioned in the core MDT composition, but the recommendation states

	Stakeholders asked for clarity on when and who should assess patient suitability for safely entering rehabilitation Stakeholders asked that there be consideration of the risk of harm to ME/CFS patients entering rehabilitation where physical exercise can harm patients One stakeholder suggested that "psychiatric aspects of rehabilitation" implies that post COVID-19 is a psychiatric illness	that the composition of the MDT should be based on the person and their presenting symptoms. The panel did not add detail regarding this, because they discussed that this should form part of the assessment and it is not in the scope of the guideline to determine who should assess patient suitability. As stated previously the panel concluded that there was not sufficient evidence to draw strong parallels between the conditions and concluded that there was not a need to add further text here. NICE has developed separate guidance on the management of ME/ CFS and people who have ME/ CFS should be managed according to the appropriate care pathway. The panel noted that post-COVID-19 syndrome can include both physical, psychological and psychiatric aspects and therefore rehabilitation should cover all of these, depending on the persons symptoms. Therefore, no change was made to the recommendation.
5.5	[19 comments] Stakeholders asked that possible gender differences were considered throughout the guideline It was highlighted that the term 'rehabilitation prescription' is not widely understood or commonly used, so suggested a description of the concept using other terminology. Stakeholders flagged a need to consider fatigue and adjusting activities in response to this. Some stakeholders mentioned the new ME/CFS guidelines on this area.	Equalities issues were taken into account by the panel and the equalities impact assessment describes how these were addressed. The panel discussed that the term 'rehabilitation prescription' was appropriate and have added detail about what this contains in the rationale. The panel considered this would depend on the individual patient and no change was needed to incorporate this into the wording.

	Stakeholders suggested description of ‘brain fog’ as ‘cognitive impairment (brain fog)’ Stakeholders flagged a need to include review of the rehabilitation plan as required or to account for fluctuating symptoms. One stakeholder suggested that the recommendation should contain an explanatory note which states that patients require a period of convalescence prior to starting rehab There were similar concerns around graded exercises programmes causing harm/relapses. Stakeholders preferred the term “pacing”. One stakeholder suggested using relevant parts of other rehabilitation guidance to provide more detail on MDT services One stakeholder queried what advice was to be given on symptom management.	NICE has developed separate guidance on the management of ME/ CFS and people who have ME/ CFS should be managed according to the appropriate care pathway. The panel noted that the term ‘brain fog’ is well recognised and no change was made to the recommendation. The panel considered that the rehabilitation prescription would be reviewed regularly, and this did not need stating in the recommendation. There is also a separate guideline section on follow up and monitoring. The panel agreed that a note on convalescence before rehabilitation was not required, as the rehabilitation prescription is an individualised plan which will take the need for rest into account. As stated previously, the panel concluded that there was not sufficient evidence to draw strong parallels between the conditions and concluded that the terms used were appropriate for what is known about this condition at this time. The panel agreed not to use relevant parts of other guidance to provide more detail on MDT services as PCS is a new entity about which little is known, and it is not possible to extrapolate from other guidance at this time. This panel agreed that it is not possible to advise on symptom management in this guideline due to the wide range of associated symptoms and this would be done on an individual patient basis.
5.6	[14 comments]	The panel were unable to provide more information about which apps would be used to track symptoms, because the

	Stakeholders asked for consideration of the panel about what specific apps for tracking symptoms, goals etc, and whether they mean simply a step tracking app or something more specific. One stakeholder highlighted that NHS Wales are currently developing a COVID rehab app which should be available before Christmas.	evidence on this was not reviewed and therefore the panel were not able to make recommendations on this. The panel agreed that they meant specific apps for tracking symptoms and goals. The panel noted this comment.
5.7	[13 comments] There were multiple comments suggesting that recommendation should be applied not only to older people and children, but to any patient with extra support needs, e.g. people living in isolation, people with comorbidities, people with disabilities etc.	The panel noted the stakeholder comments, but felt that the recommendation was appropriate, because older people are at risk of rapid decline unless appropriate support is in place. The panel also noted that the recommendation already takes social isolation into account.
5.8	[8 comments] There was concern expressed around inconsistent wording. In particular, it is not possible for children to have post- COVID-19 syndrome after only 4 weeks. It was also noted that the reasons for early referral in children should be brought out, as these are most likely to relate to exclusion of other conditions. Attention should also be drawn to considering the mental health and wellbeing needs of children.	The term early referral has been removed from the recommendation, as the referral criteria are now the same for adults and children. Children, like adults can have ongoing symptomatic COVID-19 4 weeks after acute COVID-19. The panel agreed that mental health and wellbeing needs of children were important, but that it was not appropriate to add it to this recommendation.
6.1	[9 comments] Stakeholders asserted that this depends on local availability. Some comments indicated that this should be led by primary care with MDT rehab to support, guided by AHP, that there shouldn't be 'over-medicalisation'. Others asserted that it should take into account barriers to access (rural, travel issues). Some stakeholders were concerned that the audience for the recommendations was not clear. One stakeholder advised that any plan should be recommended by the healthcare professional and agreed with the person suffering. They asserted that the process should be healthcare professional led.	Text has been added to the beginning of this section to clarify which audience this recommendation applies to. This outlines which settings this should happen in. The panel considered the comments and agreed that no changes were required. This was because they noted that

	One stakeholder stressed the need for family and carers to be involved for those unable to self-manage One Stakeholder stressed the need to take into account the relapsing-remitting nature of the condition and to provide recognition and reassurance that symptoms may fluctuate.	this should be shared decision making between the healthcare professional and patient and should take into account the persons individual symptoms and situation. The panel acknowledged that family and carers may need to be involved but did not feel that this information should be added to the recommendation. The panel noted that a recommendation had been made on the fluctuating nature of symptoms (recommendation 2.3).
6.2	[6 comments] Stakeholders commented that this should mention having the presence of a carer to support the person with follow up appointments and monitoring (e.g. to help with remote digital monitoring) Stakeholders supported the recommendation, 1 of these noted a need to get a balance between clinician and person preferences.	The panel agreed but noted that this recommendation was about the location of follow up, and this did not prevent a carer being present to support the person.
6.3	[6 comments] Comments included caution that a focus on symptoms could encourage a focus on illness and that monitoring should be tailored and access issues considered.	The panel concluded that the recommendation was appropriate, and person centred, as it enabled clinicians to tailor monitoring on an individual basis.
6.4	[11 comments] Stakeholders commented that the recommendation was generally vague and flagged that unless self-monitoring was accompanied by explicit instructions and detail it can lead to unnecessary anxiety in people. They also suggested it include detail of who to report back to – MDT or GP and thresholds for further action. 3 stakeholders noted that it would be more useful if the parameters that arouse suspicion were mentioned here and asked for clarification on whether it is supported or not. They also noted that it may exclude vulnerable groups (extending digital exclusion). 1 stakeholder stressed the need to ensure home investigation equipment is provided to people who cannot afford them, and that people understand the limitations of these devices.	The panel noted the comments from stakeholders and amended the recommendation to state that is should be ‘supported self-monitoring’ and that health care professionals should ‘Ensure that people have clear instructions and parameters for when to seek further help.’

	1 stakeholder suggested inclusion of a symptom diary as a possible means of self-management, particularly with regards to monitoring energy levels and exercise capacity and recognising triggers for post-exertional malaise. 1 stakeholder suggested self-monitoring at home should also be considered in the earlier weeks post infection, and not reserved for 12+ weeks after infection	The panel noted that there was a recommendation in section 5 on the use of symptom diaries as part of self-management. This recommendation applies to a person with ongoing symptomatic COVID-19 and post COVID-19 symptom, so applies to anyone with symptoms for more than 4 weeks after acute COVID-19
6.5	[9 comments] 2 stakeholders agreed with the recommendation. 1 suggested that National Voices 'I' statements be referred to as a standard for shared decision making. 3 stakeholders requested that red flags should be listed here in more detail. 1 stakeholder commented that it should not be assumed that new symptoms are related to long COVID and another noted that Long COVID symptoms can present weeks or months after initial illness. Another noted the use of symptom diaries can be useful in noting how symptoms fluctuate.	The recommendation was amended to cross refer to a recommendation in section 2 about signs and symptoms indicating that an urgent referral may be needed The panel noted that there was a recommendation in section 5 on the use of symptom diaries as part of self-management.
7.1	*[12 comments]* There was a suggestion that the recommendation should advise checking of patient consent to share information at the earliest opportunity (as not automatic). There was a suggestion to clarify both who needs to share information, and with whom it needs to be shared., for example sharing of relevant information with carers. It was also suggested that clinical information should be shared digitally or electronically (where there are opportunities).	The panel did not agree that this needed adding to the recommendation, as this should be part of a clinician's approach without having to specify it in a guideline. They did not agree that it needed clarifying who needs to share information with whom, as this would vary. Detail about encouraging digital sharing was added to the recommendation by the panel.

	There was a suggestion to list relevant documentation to share, including referral, assessment and screening materials There was a suggestion to make reference to ensuring that the patient understands their follow up/continuity of care plan (as they can become confused if information is not clear and well signposted) There was a suggestion to reword or elaborate on this recommendation, as patient records not routinely available in all places. Stakeholders questioned whether there needs to be comment in guideline on possible infrastructure change to support information sharing and care continuity.	The panel updated the list of suggested documents to share. No change made as the panel agreed that this will depend on the individual patient Reworded to take this into account Wording amended to encourage digital sharing of information.
7.2	*[6 comments]* There was a suggestion to clarify which baseline measures, and when the baseline should be taken. There was a suggestion to mention information sharing of ongoing outcome assessments, not only the baseline. Stakeholders suggested inclusion of functional abilities using validated measures and inclusion of aspects of cognition which may impact on informed care and treatment decision making. There was a suggestion to elaborate on what sort of tools are being referred to.	Baseline measures could relate to different time-periods depending on the situation, so the panel agreed that no further information should be added. The panel agreed to add sharing of ongoing assessments, and functional abilities to the list of examples in this recommendation. The reference to validated tools was removed from the recommendation as the panel considered that these would vary depending on which setting the person was in.
7.3	*[8 comments]* Stakeholders suggested that this recommendation needed strengthening. They asserted that MDTs are not just 'thinking about', but ensuring improvements happen.	The panel agreed that this recommendation should be strengthened and has been merged with 7.1 and strengthened as per the stakeholder comment.

	Stakeholders suggested that this is a 'must do' [e.g. remove, 'Think about ways to…'], including to enable patient involvement. Stakeholders questioned the feasibility of process for NHS currently (due to available technology and personnel). Stakeholders suggested adding mention of system compatibility, and economic considerations for patient use of IT. There was a suggestion to clarify the level of integrated working (e.g. healthcare system, teams discussing work, or individual patient level). Stakeholders suggested clarification of who needs to do the thinking, as this is about system and operational changes. Stakeholders flagged a need to define the required change and who is responsible for implementing it. Stakeholders suggested a curated and maintained repository that is signposted to. Stakeholders suggested clarification, e.g. whether COVID MDT will be responsible for seeking specialist advice directly from hospital and asked how Primary Care Networks and secondary care specialists will integrate with COVID hubs.	The panel agreed that this recommendation was good practice and acknowledged that there may be challenges in implementing it. The panel highlighted that local commissioning groups should be involved in implementing effective information sharing.
7.4	*[9 comments]* Stakeholders suggested that recommendation 7.4 should move to section 8. One stakeholder suggested inclusion of aspects of women's health in multidisciplinary care, Stakeholders suggested more specifics around who is intended as the single point of contact.	The panel were satisfied that this was the right section for the recommendation. Please see responses to recommendation 8.2 for MDT composition. The panel agreed that it was not practical to specify who should be a local point of contact as this would depend on local arrangements. The panel also agreed that it was

	Stakeholders queried where an SPC or care coordinator would be based (e.g. primary care, psychiatry) and asked whether there would be thresholds (e.g. if symptoms merit). There was a suggestion to be more explicit on who's responsibility this should be (e.g. PCS clinic or GP) and if this is an additional service. Stakeholders suggested the recommendation should be more explicit re facilitating effective services in terms of staffing, structure and funding.	beyond the scope of the guideline to comment on local commissioning issues.
8.1	[25 comments] Stakeholders suggested that the wording of 'consider' should be reviewed and potentially made stronger in line with 8.2. Stakeholders commented that involvement of rehabilitation consultants should be made explicit as distinct from 'medical doctor'. Stakeholders flagged a need to cross refer to NHSE commissioning guidelines on long COVID clinics, and any equivalents in devolved nations. Stakeholders argued the case for recommending usual care until stronger evidence emerges for alternative models.	This recommendation has been strengthened to state 'provide' and the reference to one-stop clinics has been removed, as this pertains to England only. Rehabilitation medicine is listed as a core component of the MDT in recommendation 8.2. NHSE commissioning guidance is not cross referred to here, because it did not form part of the evidence review. The panel made recommendations based on the best available evidence, expert testimony and their experience, taking into account usual care.
8.2	[24 comments] One stakeholder suggested inclusion of paediatricians in the MDT.	This recommendation was amended to say that 'Additional expertise may be needed depending on the age and symptoms of the person' and text has been added to the

	One stakeholder felt physiotherapy may not be appropriate/applicable to this patient group. One stakeholder suggested the core team include a pharmacist. One stakeholder flagged the importance of speech and language therapy as part of core team.	rationale to say that a paediatrician may be appropriate if the person experiencing long-term effects of COVID is a child. The panel agreed that physiotherapy was appropriate to have on the core MDT list. The panel agreed that a pharmacist or speech and language therapist could be part of the team, depending on the person and their symptoms and highlighted this in the rationale.
8.3	*[8 comments]* It was suggested that this recommendation should emphasise development of clinical networks (primary/ secondary/ tertiary care) to discuss patient's experiences, share expertise and conduct research. A national registry of long COVID-19 patients was also suggested. There was a suggestion to amend this recommendation to make sharing knowledge, skills and training more explicit, through recommending establishment of facilitating structures, e.g. local hubs to create cohesive and collaborative learning networks There was concern re the 1-minute sit-to-stand test (see general comments also) and a- suggestion to highlight the potential issues around doing these in the community, especially if ECG was not monitored. There was a suggestion that use of the sit to stand tests should be a research recommendation only, until evidence is generated. There was a suggestion to expand the recommendation to include 'appropriate cognitive assessments', as well as breathlessness training (due to potential impact on return to work and other activities).	It was concluded that clinical networks are developed at a regional level according to local needs and national registries are developed by NHS Digital. It was concluded that clinical networks are developed at a regional level according to local needs. Shared learning examples will be considered for addition to the tools and resources section of the guideline web page to assist in developing networks Please see recommendation 3.5 for alterations made to recommendations on using sit- to- stand tests. The panel agreed that extra wording should be added to say this should only be done if appropriate. The panel agreed that this did not need to be included because the list was intended to provide examples only, and not meant to be exhaustive.

8.4	*[14 comments]* Stakeholders queried whether the guideline could be more solution-focused and commented on how to achieve the agreement of local referral pathways.	The panel agreed that no change would be made, as local referral pathways would depend on local commissioning arrangements.
	One stakeholder suggested inclusion of the word, 'integrated 'to this recommendation.	The panel agreed with the suggestion and the text has been amended to include the word ‘integrated’.
	Specialist services One stakeholder suggested clarification on what is meant by specialist services. One stakeholder suggested the recommendation needed to be clear on what specialist services can offer, and how to access them appropriately without over-medicalising.	The panel noted that healthcare professionals are familiar with the term ‘specialist services’ and therefore no change was made.
	There was a suggestion to include non-public sector services as part of referral pathways (e.g. community organisations providing support to patients and carers) and social care	The panel noted that voluntary sectors were referred to in recommendations 5.1 and agreed it was not appropriate to add more detail here.
	There was a suggestion that emphasis should be on MDT assessment, diagnosis and treatment.	Referral for MDT assessment is reflected in the recommendation. 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. However, 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.
	There was a suggestion to develop specific referral pathways for each affected body system.	Specific referral pathways for each affected body system were considered to be beyond the scope of the guideline and would depend on local commissioning arrangements.
	There was a suggested need for a new recommendation to ensure the rehabilitation pathway should reflect the needs of BAME patients.	The needs of BAME patients were considered as part of the equalities impact assessment, which notes that there is some evidence of poorer outcomes from COVID-19 in black, Asian and minority ethnic populations. It was considered important to consider these populations when drafting recommendations, However, the prevalence of prolonged COVID-19 symptoms in black, Asian and minority ethnic groups is currently not known, and therefore a priority research recommendation was included.
Rationale	There were a number of comments relating to the case definition and these are presented in the relevant section above.	Please see the section in this document on 'case definition' for details.
	One stakeholder commented that the YRS is based on ADL post ICU so will not be relevant to many people with Long COVID and may miss a lot of people	Detail has been added to the relevant recommendation and the rationale that screening questionnaires should not be used alone, as they are not validated and may miss some key symptoms.
	Comments asserted that there is no evidence that people with Long COVID have increased anxiety and depression and expert testimony should not be used as evidence in this context Stakeholders commented that issues around psychological assessment prior to rehabilitation could lead to inequalities of treatment	The panel acknowledged that people experiencing the long-term effects of COVID do not necessarily have increased anxiety and depression, but balanced this against the evidence that the long terms effects of COVID 19 include physical, psychological and psychiatric symptoms and wanted to ensure that a person receives holistic assessment and treatment.

	One stakeholder commented that identifying criteria for referral should be a priority given the potential for organ damage.	The panel agreed that criteria for referral are important but did not feel they had sufficient evidence to inform this. The panel noted that recommendations highlight that that healthcare professionals should refer people urgently to the appropriate service, if the person has signs or symptoms which indicate a serious underlying illness.
	One stakeholder commented that GPs will likely find it hard to decide when to refer older people to MDT and highlighted that there were a local frailty assessment service MDT which could do a CGA then this would be as good.	The panel discussed that the presentation of symptoms in older people and acknowledged they may be similar to a number of other illnesses, but they agreed that if the healthcare professional suspects Post COVID Syndrome then the person should be referred for appropriate assessment and/ or rehabilitation.
	One stakeholder asked for echocardiography to be listed on page 18.	The panel agreed that echocardiography should not be added here but noted that did not exclude undertaking the test in a person whose symptoms indicated that they should have one.
	There were 2 comments from ME/ CFS groups that were critical of lack of mention of these conditions and the ignorance of possibility that some people may have CFS/ ME and risks of exercise programmes,	As mentioned previously, ME/ CFS is not in the scope of this guideline and NICE is developing separate guidance on ME/ CFS.
Priority research recs		
1	• Stakeholders suggested adding a new research question around diagnosis of potential sub-groups within post-COVID syndrome and a related research question around the potential impact of treatment/management decisions during acute COVID on risk of developing long Covid e.g. early ventilation	A new research recommendation on different subgroups of post-COVID-19 syndrome and how are they diagnosed was not considered necessary, as this subgroup's characteristics are incorporated by the wording of the research recommendation on risk factors.

		The impact of treatment/management decisions on risk of developing post-COVID syndrome, such as early ventilation, is encompassed as a risk factor by the general wording of the research recommendation on risk factors.
2	The exercise research recommendation attracted the most comments with contributors suggesting that it should be reworded to acknowledge the potential harms of exercise programmes/exertion and that exercise interventions need to be individually tailored. Stakeholder also suggested taking account of potential effects of rest and autonomic rehabilitation. The point was made that referring to interventions for a syndrome was too broad and that a more meaningful approach would be to structure by specific symptoms or key groups of symptoms, e.g. breathlessness, anxiety, cognition. There were many suggestions for additional research recommendations encompassing specific settings, patient groups and interventions including: • Sex differences • Social environment differences • HRT, menopause, menstruation and hormonal effects	In the light of the numerous comments on exercise interventions additional questions on exercise were added to this research recommendation: What is the clinical effectiveness of exercise interventions for people with post-COVID-19 syndrome? Does effectiveness vary for different population groups (for example sex, age, socioeconomic group, black, Asian and minority ethnic group communities or people with learning disabilities)? The population covered by the guideline is post COVID 19 syndrome. The case definition explains that PCS usually presents with clusters of symptoms, often overlapping, which can fluctuate and change over time and can affect any system in the body. Therefore, the research recommendation was worded to target the syndrome but aimed at also encompassing interventions for specific symptoms. The following new question was added to the research recommendation to incorporate different population groups:

	• Effectiveness of training informal carers of patients with post COVID-19 syndrome • Safety of vaccinations including for COVID • What can be learned from therapies for other post infection multisystem disorders • Effectiveness of primary care interventions • Over the counter vitamins and supplements • What is the underlying pathophysiology • Prevalence in hospitalised vs non-hospitalised patients • Impact of early specialist referral on patient outcomes • Effect of illness beliefs, social support, provision of information and advice on self-management • Early use of steroids and antivirals • Specific effects in people with neurological conditions • What is the healthcare professional skill mix required to provide appropriate multidisciplinary care? • Viral shedding and infectivity • Gastrointestinal effects and nutritional aspects • Impact on existing conditions • Determining vulnerable groups A few comments concerned the importance of research data collection and the need to discuss opportunities to take part in rehabilitation trials with patients.	Does effectiveness (with regards to interventions for managing long term effects of COVID-19) vary for different population groups (for example sex, age, socioeconomic group, black, Asian and minority ethnic group communities or people with learning disabilities)? The panel considered other additional suggestions for research recommendations, but agreed that the existing key research recommendations should be retained as priority. Some of the suggestions were already encompassed in the wording of the existing recommendations. Other suggestions were outside the scope of the guideline.

		Research data collection is encompassed within the scope of the research recommendation and a separate research recommendation was not considered necessary.
3	Stakeholders suggested two main considerations for research recommendations: 1) whether to include other equality groups in this recommendation and 2) whether to explore differences other than incidence and prevalence, e.g. differences in symptoms or service access.	When considering the stakeholder comments, the panel decided to expand on this question to include other equality groups. The question was re-written to firstly ask what the prevalence of COVID-19 syndrome is and then to identify whether this differs across difference equality groups. A new research recommendation looking at differences in symptoms across different equalities groups was added. A new research recommendation on access to services was not considered at this time, because it will be best considered when evaluating service models as they are implemented.
Other research recs		
1	One stakeholder queried whether those with occupation acquired post COVID-19 syndrome (with implication that may have particularly high exposure levels) should be a group of specific study One stakeholder made reference to role of speech and language therapists	A new research recommendation specifically for those with occupational acquired post-COVID-19 syndrome was not drafted at this time, this population would be considered across all review questions as a named equalities group. Text was added to the Equalities Impact Assessment document to ensure this.

		The panel agreed the core expertise that a multidisciplinary team could include and, because symptoms are so wide ranging, many other areas of expertise could also be added as needed, including speech and language therapy. This is reflected in recommendation 8.2 which states that additional expertise may be needed depending on the age and symptoms of the person.
2	Add pregnant women as a subgroup within this recommendation.	Pregnant women have been added as a subgroup within this recommendation.
3	No comments	
4	Consider clarifying that screening tool should screen for physical and psychological symptoms of post COVID-19 syndrome	Physical, psychological and psychiatric aspects have been added to the research recommendation.
EIA	[20 comments] **Sex** Stakeholders highlighted that there is a "risk that women feel marginalised, have experienced misogyny or being patronised, or have had previous experiences with an insensitive healthcare service and that could create barriers to engagement with healthcare services". They noted that women have experienced as having their symptoms dismissed as 'in the mind'. Women often have more informal care responsibilities which can in turn impact their ability to look after their own health, particularly since the people they support (children, older relatives etc) are currently often unable to access their normal support services due to the ongoing situation. **Race**	The equalities issues raised at consultation were discussed by the panel and details of how they have been addressed are included in section 4 of the EIA.

	One stakeholder noted that more emphasis in needed to say that the issues discussed around higher comorbidities should not be limited to biological factors but should include that comorbidities can be due to social determinants of health and systemic racism that Black, Asian and minority populations experience. **Disability** One stakeholder suggests that people with disabilities who are immunocompromised may fear accessing care due to the risk of COVID reinfection. **Socioeconomic factors** One stakeholder highlighted that parents with post-COVID-19 syndrome who need to seek in-person medical care may face barriers in securing childcare for their children, while clinics limit the number of visitors due to COVID precautions. This may lead to missed appointments or inability to attend in-person appointments. There was also the mention of financial barriers for people with post-COVID-19 syndrome having difficulty accessing disability benefits. **Gender reassignment** One stakeholder highlighted existing evidence related to gender reassignment and health outcomes which shows a number of factors that can dissuade trans people from seeking healthcare e.g., lack of providers that are knowledgeable on the topic, discrimination etc. **Pregnancy and maternity** One stakeholder highlighted that the effect on the unborn child of maternal COVID-19 infection is currently little understood and needs monitoring. Any	

	concerns raised by mothers should be responded to by healthcare practitioners. **Sexual orientation** One stakeholder added that LGBTQ+ citizens have far higher incidences of mental ill health **Carers (in relation to age and disability)** One stakeholder highlighted that there are limited arrangements for the involvement of carers in supporting an individual with healthcare the difficulties faced by older people or those with a disability may be further exacerbated. **Digital accessibility** There are additional concerns around access to digital media. As well as concerns highlighted previously about internet access or familiarity of using digital media, stakeholders note that people with post-COVID-19 syndrome may be experiencing fatigue, brain fog and other symptoms that may prevent access to these services. This is something to bear in mind especially around recommendation 5.1. One stakeholder noted that there are language barriers due to Your COVID Recovery only being available in English. **Other** One stakeholder noted the importance of considering equalities interjectionally as well as separately as these might lead to additional barriers. One stakeholder noted that people with post-COVID-19 syndrome may be experiencing new difficulties in ADLs and may also have new transportation	

	barriers due to new mobility, cognitive, or sensory impairments which may create barriers in attending face to face appointments. One stakeholder noted that people who have occupational-acquired COVID-19 could be mentioned as a separate group, particularly as some have experienced reinfection.	