



**Health  
Information  
and Quality  
Authority**

An tÚdarás Um Fhaisnéis  
agus Cáilíocht Sláinte

# **International review of clinical guidelines and models of care for long COVID**

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*Safer Better Care*

## **About the Health Information and Quality Authority (HIQA)**

The Health Information and Quality Authority (HIQA) is an independent statutory authority established to promote safety and quality in the provision of health and social care services for the benefit of the health and welfare of the public.

HIQA's mandate to date extends across a wide range of public, private and voluntary sector services. Reporting to the Minister for Health and engaging with the Minister for Children, Equality, Disability, Integration and Youth, HIQA has responsibility for the following:

- **Setting standards for health and social care services** — Developing person-centred standards and guidance, based on evidence and international best practice, for health and social care services in Ireland.
- **Regulating social care services** — The Chief Inspector within HIQA is responsible for registering and inspecting residential services for older people and people with a disability, and children's special care units.
- **Regulating health services** — Regulating medical exposure to ionising radiation.
- **Monitoring services** — Monitoring the safety and quality of health services and children's social services, and investigating as necessary serious concerns about the health and welfare of people who use these services.
- **Health technology assessment** — Evaluating the clinical and cost-effectiveness of health programmes, policies, medicines, medical equipment, diagnostic and surgical techniques, health promotion and protection activities, and providing advice to enable the best use of resources and the best outcomes for people who use our health service.
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- **National Care Experience Programme** — Carrying out national service-user experience surveys across a range of health services, in conjunction with the Department of Health and the HSE.

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## List of abbreviations used in this report

|               |   |
|---------------|---|
| <b>AAPMR</b>  | American Academy of Physical Medicine and Rehabilitation          |
| <b>AAP</b>    | American Academy of Pediatrics                                    |
| <b>ACC</b>    | American College of Cardiology                                    |
| <b>CAMFiC</b> | Catalan Society of Family and Community Medicine                  |
| <b>CCS</b>    | Canadian Cardiovascular Society                                   |
| <b>CDC</b>    | Centres for Disease Control and Prevention                        |
| <b>CGA</b>    | comprehensive geriatric assessment                                |
| <b>ESCMID</b> | European Society of Clinical Microbiology and Infectious Diseases |
| <b>EuGMS</b>  | European Geriatric Medicine Society                               |
| <b>GNS</b>    | German Neurological Society                                       |
| <b>ISP</b>    | Italian Society of Pediatrics                                     |
| <b>ISS</b>    | Istituto Superiore di Sanita                                      |
| <b>NICE</b>   | National Institute for Health and Care Excellence                 |
| <b>PASC</b>   | post-acute sequelae of SARS-CoV-2 infection                       |
| <b>PESE</b>   | post-exertional symptom exacerbation                              |
| <b>PICS</b>   | post-intensive care syndrome                                      |
| <b>RACGP</b>  | Royal Australian College of General Practitioners                 |
| <b>RCGP</b>   | Royal College of General Practitioners                            |
| <b>SIGN</b>   | Scottish Intercollegiate Guidelines Network                       |
| <b>WHO</b>    | World Health Organization   |

## **Acknowledgements**

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Not all members of the Evidence Synthesis Team are involved in the response to each research question.

### **Conflicts of interest**

None declared.

## Key points

- This review aimed to address the following research question:
  - What clinical guidelines and or models of care are currently available for the diagnosis and management of long COVID internationally?
- In total, 24 guidelines and two models of care were included in the review.
- The diagnosis and management of long COVID in general (also referred to as post-acute sequelae of SARS-CoV-2 infection (PASC), post-COVID condition, persistent or ongoing symptomatic COVID-19 disease, post-COVID syndrome) were primary topics for 17 of the included guidelines and one model of care. Seven guidelines and one model of care focused on specific long COVID sequelae, such as cardiac complications, breathing discomfort, fatigue, cognitive and neurological symptoms.
- Eighteen guidelines and one model of care were national-level, three guidelines were international-level and the remaining guidelines and model of care were regional-level. Guidelines and models of care were produced in Australia, Canada, Germany, Italy, New Zealand, Singapore, Spain, Switzerland, the UK and US.
- Two guidelines were specific to paediatric populations, one guideline was specific to older adults' rehabilitation post-COVID and three guidelines were specific to primary care.
- Nine guidelines and one model of care were published and or updated since February 2022, 15 guidelines and one model of care were published in 2021, and one guideline did not report the date it was published. Twelve guidelines were described as living guidelines or referenced maintenance of guidance statements.
- Definitions of long COVID:
  - Fourteen guidelines and two models of care defined long COVID as symptoms that persist for four or more weeks following acute COVID-19.
  - Four used the National Institute for Health and Care Excellence (NICE) clinical case definition where long COVID refers to both



ongoing symptomatic COVID-19 (from 4 to 12 weeks) and post-COVID-19 syndrome (12 weeks or more).

- Two guidelines used the World Health Organization (WHO) definition of long COVID, defined as the continuation or development of new symptoms three months after the initial SARS-CoV-2 infection, with these symptoms lasting for at least two months with no other explanation.
- Five guidelines defined long COVID as symptoms persisting for 12 weeks or more post-infection; of which one included a caveat that long COVID may be considered where the possibility of an alternative diagnosis is also being assessed.
- Three guidelines (from the Royal Australian College of General Practitioners, the European Geriatric Medicine Society and Singapore) did not explicitly apply a timeframe.
- The American College of Cardiology model of care included two definitions specific to cardiovascular sequelae of long COVID (PASC-related cardiovascular disease and PASC-related cardiovascular syndrome).
- Ten guidelines and one model of care achieved an overall assessment score of greater than 70% in the AGREE-GRS quality appraisal. The narrative summary of the recommendations of interest focused on these higher quality guidelines and model of care, as well as those relating to subgroups such as older adults and paediatrics.
- Recommendations on diagnosis:
  - There was an emphasis on the broad and fluctuating range of symptoms associated with long COVID. The majority of the guidelines referenced the need to identify potential causes or conditions that may reasonably explain, be related to, or exacerbate the symptoms, with the potential for a diagnosis of long COVID once alternative diagnoses have been ruled out.
  - Nine higher quality guidelines and one higher quality model of care recommended symptom-based assessments and tests tailored to the symptoms reported by the individual.
  - For patients hospitalised during the acute COVID-19 phase, the NICE guideline recommended that a healthcare professional in secondary

care offers a follow-up consultation at six weeks post-discharge to check for new or ongoing symptoms or complications.

- The Alberta, Canada model of care recommended that hospitalised patients with COVID-19 be screened for rehabilitation needs at each transition of care.
- Guidelines from NICE and the Australian National COVID-19 Clinical Evidence Taskforce highlighted the need for a holistic, person-centred approach to assessment for those with ongoing symptomatic COVID-19 or suspected long COVID. These guidelines, and the guideline from the American Academy of Physical Medicine and Rehabilitation recommended facilitation of shared decision-making with the patient.
- The New Zealand Ministry of Health guideline recommended consideration of specific 'red flag' symptoms in children and young adults presenting with ongoing symptoms of COVID-19.
- The American Academy of Pediatrics recommended a conservative approach to assessment of children and adolescents during the 4 to 12 weeks post infection with SARS-CoV-2 due to harm that may arise from excessive testing.
- For symptoms that persist beyond 12 weeks and impact on the activities of daily living of the child and or adolescent, the American Academy of Pediatrics recommended additional diagnostic testing and or referral to a multidisciplinary paediatric post-COVID-19 clinic. Where a multidisciplinary paediatric post-COVID-19 clinic is not readily available, referral to a paediatric medical subspecialist on the basis of the most problematic signs and symptoms was recommended.
- The European Geriatric Medicine Society recommended a comprehensive geriatric needs assessment for older adults recovering from COVID-19.
- Recommendations on treatment and or management:
  - Three guidelines recommended certain symptoms of long COVID (for example, dyspnoea) be treated with well-established clinical approaches using existing guidelines and clinical expertise (such as, referral to pulmonology). One guideline explicitly recommended

against the use of emerging or unproven therapies that were not assessed in randomised trials with appropriate ethical approval.

- The Swiss guideline recommended inhaled or systemic steroid treatment for patients who present with new obstructive lung disease following COVID-19, inhaled steroids for those with persistent cough following COVID-19, and evaluation to determine if a systemic steroid trial is required for those presenting with interstitial abnormalities.
- Three guidelines highlighted the need for a holistic, person-centred approach to the management of long COVID symptoms, including facilitation of shared decision-making with the patient.
- Recommendations for the management of long COVID included provision of information on self-management, sources of advice and support, education and skills training on energy conservation techniques, coupled with support from integrated and coordinated primary and community care, rehabilitation and mental health services, or referral to an integrated multidisciplinary service.
- Recent updates to the Australian National COVID-19 Clinical Evidence Taskforce guideline and NICE guideline recommended the provision of psychosocial, psychological and psychiatric support, if indicated, for people with signs and symptoms of a new or exacerbated pre-existing mental health condition following acute COVID-19, and urgent referral for psychiatric assessment if they have severe psychiatric symptoms or are displaying a high risk of self-harm or suicide, respectively.
- Three additional guidelines were identified since the final literature search on the 22 September 2022. These included the Korean preliminary guidelines for the clinical evaluation and management of long COVID, AAPMR guidance for PASC in children and adolescents and AAPMR guidance for autonomic dysfunction in PASC. Although these guidelines were not interrogated in the same way as those included up to the final search date, their recommendations were largely consistent with our findings.
- Guidelines consistently recommended that clinical records and rehabilitation plans should be shared in a timely manner between services.

- Some guidelines provided symptom specific recommendations; these included recommendations for the management of post-exertional symptom exacerbation, pain, breathing discomfort, fatigue, cognitive dysfunction and cardiac complications.
- The New Zealand Ministry of Health guideline recommended energy conservation strategies for children and young people with fatigue, provision of symptom-guided or paced return to sport for those with cardiac symptoms, and targeted psychological support for those who experienced fatigue-related frustration and difficulties with pacing. In addition, they recommended support for, and monitoring of, caregiver fatigue.
- For children and or adolescents with ongoing symptomatic COVID-19 or long COVID-19, referral for specialist advice (that is, referral to a primary care paediatrician) from four weeks was recommended by the NICE guideline and two paediatric guidelines from the American Academy of Pediatrics and the Italian Society of Paediatrics.
- The New Zealand Ministry of Health guideline recommended referral for specialist and or multidisciplinary assessment and support for older adults in the presence of mobility issues, communication issues, nutritional and swallowing issues, respiratory issues and fatigue.
- The European Geriatric Medicine Society recommended that treatment plans for older adults be based on comprehensive geriatric needs assessments conducted across a number of domains (somatic, functional, psychological, existential, and social) and shared decision-making. They also advised that COVID-19 patients discharged from hospital after ICU admission can be affected by a variety of problems, such as the post-intensive care syndrome; as such, they require extra attention in relation to malnutrition, breathing issues, swallowing difficulties and oropharyngeal dysphagia.
- Recommendations on service planning:
  - There was an emphasis on integrated multidisciplinary services (including specialists in allied health, clinical psychology, nursing, rehabilitation medicine) based on local need and resources led by a physician with relevant skills and experience.

- Core functions in service organisation for long COVID included: standardised assessment tools to systematically identify long COVID symptoms and rehabilitation outcome measurement; a system to allow patient follow-up; and an onward referral system.
- Three guidelines recommended agreement of local, integrated referral pathways between hospital, primary and community-based care, rehabilitation and specialist services, specialist mental health services and multidisciplinary assessment clinics (where available) with multidisciplinary team meetings to facilitate coordinated care.
- The American Academy of Pediatrics recommended a team-based approach to service planning for children and or adolescents with long COVID coordinated by the primary care paediatrician; including medical, surgical, occupational and behavioural specialists, as needed.
- The European Geriatric Medicine Society recommended a flexible and interdisciplinary approach to geriatric rehabilitation with collaboration across healthcare disciplines, depending on the patient's needs.
- For people with disabilities and their families, the New Zealand Ministry of Health guideline recommended a holistic approach to service planning. Tailored supports for people with disabilities were also recommended as well as the involvement of experts in disability rehabilitation in long COVID management. It recommended that people with disabilities be prioritised for assessment and treatment and that accessible communication, information, and treatment should be planned for, and available to, the individual.
- In general, across guidelines, it is recommended that those who may have difficulty accessing services due to health inequities should be supported in accessing assessment and treatment and or management services.
- The HSE's current interim model of care proposes a three pillar approach to a national post-COVID service: 1) patient-led rehabilitation and recovery; 2) general assessment, support, and rehabilitation; and 3) specialist assessment, support, and rehabilitation. Approaches and recommendations in the interim model of care are broadly consistent with those identified in this international literature review with the exception that it does not specifically emphasise the need for standardised assessment tools or for structured patient follow-up.

- Guidelines differed in their definition of long COVID. Literature searches undertaken by guideline groups highlighted that the evidence base for the diagnosis and management of long COVID is still emerging. Given this, guideline recommendations were typically conditional or consensus based. It is expected that the approaches adopted will change as the evidence base evolves.

## 1 Background

In October 2022, the World Health Organization (WHO) reported that over 623 million individuals have been infected with SARS-CoV-2 worldwide since the identification of COVID-19 in late 2019.<sup>(1)</sup> Typical signs and symptoms of COVID-19 include fever or chills, cough, shortness of breath or difficulty breathing, fatigue, muscle or body aches, headache and new loss of taste or smell. Acute COVID-19 is characterised by signs and symptoms of COVID-19 lasting up to four weeks.<sup>(2)</sup> However, prolonged and persistent symptoms can occur after the acute infection period; this is referred to as long COVID.<sup>(3)</sup> Other terms that have been used for these prolonged and persistent symptoms include, post-acute COVID-19, post-acute sequelae of SARS-CoV-2 infection (PASC), long-term effects of COVID, and chronic COVID. Long COVID can affect several bodily systems, including, but not limited to, the respiratory, cardiovascular, neurological, gastrointestinal, and musculoskeletal systems resulting in various symptoms.<sup>(4)</sup>

Due to the volume of associated symptoms, there are currently no definitive diagnostic criteria for long COVID.<sup>(5)</sup> Moreover, there is a lack of consensus on the definition of long COVID. For example, the WHO has defined long COVID as the continuation or development of new symptoms three months after the initial SARS-CoV-2 infection, with these symptoms lasting for at least two months with no other explanation.<sup>(6)</sup> However, the UK's National Institute for Health and Care Excellence (NICE) defines long COVID as both ongoing symptomatic COVID-19 (that is, signs and symptoms of COVID-19 from 4 to 12 weeks) and post-COVID-19 syndrome (that is, signs and symptoms that develop during or after an infection consistent with COVID-19, continue for more than 12 weeks and an alternative diagnosis cannot explain). NICE highlights that post-COVID-19 syndrome usually presents with clusters of symptoms, often overlapping, which can fluctuate and change over time. They also report that it can affect any system in the body and may be considered before 12 weeks while the possibility of an alternative underlying disease is also being assessed.<sup>(2)</sup>

Given the lack of consensus on the diagnostic criteria and definition of long COVID, estimating its prevalence is difficult.<sup>(7)</sup> The US Centers for Disease Control and Prevention (CDC) have estimated that 20% of people with previous SARS-CoV-2 infection had at least one symptom attributable to COVID-19 more than four weeks after the initial infection.<sup>(8)</sup> Prevalence estimates from the UK Office of National Statistics in October 2022 indicate that approximately 3.5% (which equates to approximately 2.3 million individuals) of the UK population living in private households self-reported experiencing long COVID (defined as symptoms continuing for more than four weeks after the first suspected SARS-CoV-2 infection).<sup>(9)</sup> Of those



experiencing long COVID, persistent symptoms were reported in 16% of those who had a COVID-19 diagnosis less than 12 weeks previously, in 80% of those who had a COVID-19 diagnosis at least 12 weeks previously, in 46% of those who had a COVID-19 diagnosis at least one year previously and in 22% of those who had a COVID-19 diagnosis at least two years previously.<sup>(9)</sup> Of those with self-reported long COVID, 29% reported having COVID-19 prior to Alpha becoming the main variant, 11% reported having COVID-19 during the Alpha period, 19% during the Delta period, and 36% during the Omicron period.<sup>(10)</sup> A global systematic analysis that included ten ongoing cohort studies from ten countries estimated that 3.69% of individuals who contracted COVID-19 in 2020 and 2021 had long COVID symptoms at 12 weeks post-infection.<sup>(11)</sup>

A large-scale population study from the Netherlands (with a control group) evaluated long COVID prevalence while controlling for individual symptoms present before COVID-19. They found that 12.7% of individuals who had COVID-19 pre-Omicron self-reported having symptoms at three months that could be attributed to SARS-CoV-2 infection.<sup>(12)</sup>

In the absence of a definitive diagnosis for long COVID, a number of clinical guidelines recommend a holistic, person-centred approach to diagnosis, management and treatment, with an emphasis on shared decision-making.<sup>(2, 13, 14)</sup> Evidence-based guidelines on treatment for long COVID are continuing to evolve with the complexity of the condition leading to challenges in conducting robust clinical trials.<sup>(15)</sup> As such, the focus of clinical guidelines is on the management of long COVID, specifically the management of symptoms, including self-management strategies, symptom management in Primary Care with a multidisciplinary approach and individually-tailored rehabilitation plans.<sup>(13, 16)</sup> As well as guidelines, models of care have been implemented to organise long COVID healthcare services.<sup>(17)</sup> A model of care could include pathways, trajectories and frameworks for assessment aimed specifically at people experiencing long COVID.

At the request of the Health Service Executive (HSE), the Health Information and Quality Authority (HIQA) has undertaken an international review of clinical guidelines and or models of care for the diagnosis and management of long COVID. This review will inform potential updates to the HSE's interim model of care for long COVID.<sup>(18)</sup>

The aim of this review was to address the following research question (RQ):

What clinical guidelines and or models of care are currently available for the diagnosis and management of long COVID internationally?



## 2 Methods

This review adhered to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) criteria.<sup>(19)</sup>

The processes as outlined in the protocol (available at [www.hiqa.ie](http://www.hiqa.ie)) were followed. In brief, clinical guidelines and or models of care for long COVID were identified through searches of websites of organisations that produce clinical guidelines, health technology assessment (HTA) agencies and guideline repositories, as well as a grey literature search. The search of organisational websites was conducted from the 8 to 12 August 2022 (Appendix 1). Grey literature sources were searched from the 15 to 19 August 2022 (Appendix 2). All identified guidelines and or models of care were checked weekly for updates until 22 September 2022. Additionally, the grey literature search was rerun on the 22 September 2022. All newly identified records were screened for eligibility.

Eligibility criteria were: (1) international, national or regional clinical guidelines and or models of care for the diagnosis and or management of long COVID, and (2) availability in English. For each clinical guideline and or model of care, data on the country of publication, endorsing organisation and date of publication (including any planned updates) were extracted. Data on the definition, diagnosis, and management and or treatment of long COVID were also extracted. Data were extracted by one reviewer and checked by a second. Quality assessment was conducted independently by two reviewers using the Appraisal of Guidelines for Research and Evaluation Global Rating Scale (AGREE GRS) tool.<sup>(20)</sup>

The AGREE GRS tool,<sup>(20)</sup> which is based on AGREE II, was developed for use in instances where time and resources are limited. It includes the following items for assessment:

- overall quality of the process of guideline development
- overall quality of guideline presentation style
- completeness of reporting
- overall quality of guideline recommendations (that is, clinical validity)
- overall quality assessment of the guideline.

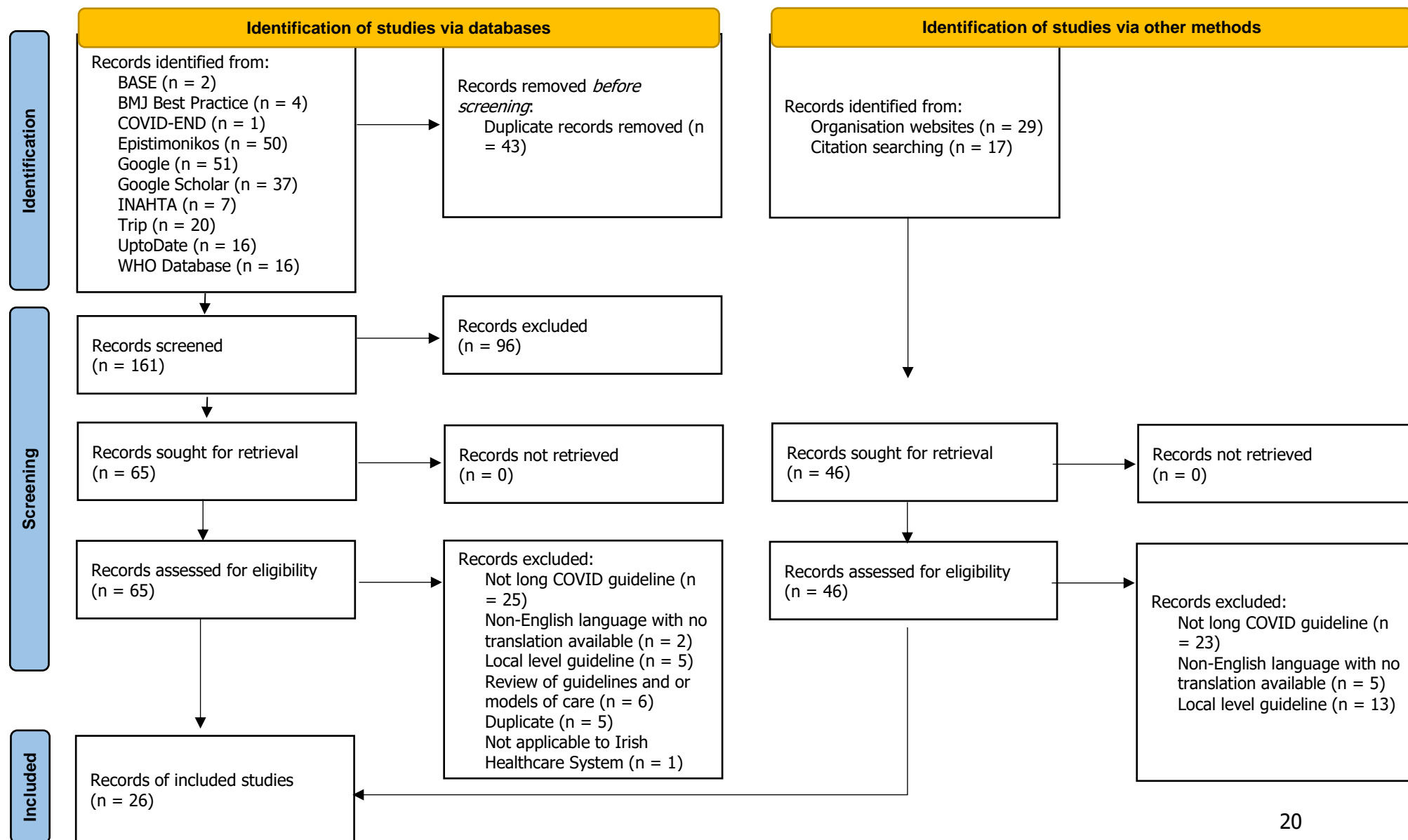
Guidelines and or models of care that achieved an overall assessment score of greater than 70% with the AGREE GRS tool were categorised as higher quality guidelines and or models of care. The narrative synthesis for this report focused on recommendations from these higher quality guidelines and or models of care, as well as recommendations specific to population sub-groups, such as older adults and paediatrics.

## **3 Results**

### **3.1 Search Results**

The collective search up until 22 September 2022 resulted in 250 citations. Following removal of duplicates, 161 citations were screened for relevance, with 111 full-texts assessed for eligibility and 85 subsequently excluded. In total, 26 guidelines and or models of care were included in the narrative synthesis. A PRISMA flow-chart summarising the search process and subsequent results is provided in Figure 3.1.

Figure 3.1 PRISMA flow diagram



## 3.2 Guideline characteristics

Twenty-four guidelines<sup>(2, 13, 14, 16, 21-40)</sup> and two models of care<sup>(41, 42)</sup> were included in this review. See Table 3.1 for a summary of the characteristics of the included guidelines and or models of care; a detailed overview is also provided in Appendix 3 and Appendix 4.

The diagnosis and management of general long COVID were primary topics for seventeen of the included guidelines<sup>(2, 13, 14, 16, 21, 23, 24, 26-28, 30, 35-40)</sup> and one model of care.<sup>(41)</sup> The remaining seven guidelines and one model of care focused on specific sequelae of long COVID, such as:

- breathing discomfort<sup>(29)</sup>
- fatigue<sup>(31)</sup>
- cognitive symptoms<sup>(34)</sup>
- pulmonary symptoms<sup>(32)</sup>
- neurological manifestations<sup>(33)</sup>
- cardiovascular symptoms.<sup>(22, 25, 42)</sup>

Eighteen guidelines<sup>(2, 13, 16, 22, 24, 27-37, 39, 42)</sup> and one model of care<sup>(42)</sup> were national-level documents, three guidelines<sup>(26, 38, 40)</sup> and one model of care<sup>(41)</sup> were regional-level documents, and three guidelines were international-level documents.<sup>(14, 21, 23)</sup> Two guidelines were specific to paediatric populations<sup>(35, 39)</sup> and one guideline was specific to rehabilitation of older adults post-COVID.<sup>(23)</sup> Three guidelines were specific to primary care,<sup>(2, 13, 24)</sup> and Royal Colleges of general practitioners also contributed to and produced three guidelines.<sup>(2, 13, 24)</sup>

### 3.2.1 Origin and developers

Six guidelines and one model of care were produced in the US, four from the American Academy of Physical Medicine and Rehabilitation (AAPMRa,<sup>(34)</sup> AAPMRb,<sup>(31)</sup> AAPMRc<sup>(29)</sup> and AAPMRd<sup>(22)</sup>) one from the CDC,<sup>(37)</sup> one from the American Academy of Paediatrics (AAP),<sup>(39)</sup> and one from the American College of Cardiology (ACC).<sup>(42)</sup> Three guidelines and one model of care were produced in Canada, one from the Government of Ontario,<sup>(26)</sup> one from the British Columbia Ministry of Health,<sup>(38)</sup> one from the Canadian Cardiovascular Society (CCS),<sup>(25)</sup> and one from the Alberta Health Services.<sup>(41)</sup> Three guidelines were produced in Australia, from the Australian National COVID-19 Clinical Evidence Taskforce,<sup>(13)</sup> the Agency for Clinical Innovation within the Government of New South Wales,<sup>(40)</sup> and the Royal Australian College of General Practitioners (RACGP).<sup>(24)</sup> Two guidelines were produced in the UK, one was developed collaboratively by NICE, the Scottish Intercollegiate Guidelines Network (SIGN) and the Royal College of General Practitioners (RCGP), hereafter referred to as the NICE guideline<sup>(2)</sup> and one was from a panel of primary and secondary care

medical practitioners in the UK.<sup>(27)</sup> Two guidelines were produced in Italy, one from the Istituto Superiore di Sanità (ISS)<sup>(30)</sup> and one from the Italian Society of Pediatrics (ISP).<sup>(35)</sup> Two guidelines were European, one from the European Geriatric Medicine Society (EuGMS),<sup>(23)</sup> and one from the European Society of Clinical Microbiology and Infectious Diseases (ESCMID).<sup>(21)</sup> One guideline each was produced in Switzerland (Swiss COVID Lung Study Group and the Swiss Society of Pulmonology),<sup>(32)</sup> Spain (Catalan Society of Family and Community Medicine (CAMFiC),<sup>(16)</sup> Germany (German Neurological Society (GNS)),<sup>(33)</sup> Singapore (Ministry of Health)<sup>(36)</sup> and New Zealand (Ministry of Health);<sup>(28)</sup> and one international guideline was produced by the WHO.<sup>(14)</sup> See Table 3.1.

### **3.2.2 Currency of guidelines**

For included guidelines and models of care, the publication date, date of update, and, where applicable, the dates covered by the most recent evidence search were extracted to inform consideration of the currency of the guideline.

Nine guidelines<sup>(2, 13, 14, 21, 22, 24, 28, 35, 40)</sup> and one model of care<sup>(42)</sup> were published and or updated since February 2022. Fifteen guidelines<sup>(16, 23, 25-27, 29, 31-34, 37-39)</sup> and one model of care<sup>(41)</sup> were published in 2021, with the AAP<sup>(39)</sup> guideline updated in 2022.

Eleven guidelines reported the literature search dates that informed them. The most recently updated guideline was produced by the Australian National COVID-19 Clinical Evidence,<sup>(13)</sup> with literature up to 26 August 2022. The NICE guideline<sup>(2)</sup> was updated in May 2022 with the most recent literature search conducted up to 21 July 2022. The ESCMID guideline<sup>(21)</sup> was published in February 2022 and was based on literature up to 31 December 2021. The ISP guideline<sup>(35)</sup> was based on literature searches conducted in November 2021. The updated WHO guideline<sup>(14)</sup> was based on literature searches conducted up to September 2021. The AAPMRa guidance on cognitive symptoms,<sup>(34)</sup> AAPMRb guidance on fatigue,<sup>(31)</sup> AAPMRc guidance on breathing discomfort<sup>(29)</sup> and AAPMRd guidance on cardiovascular symptoms<sup>(22)</sup> were based on literature up to 1 May 2021. The Alberta, Canada model of care<sup>(41)</sup> was based on literature up to March 2021. The CAMFiC guideline<sup>(16)</sup> was based on literature published up until 13 January 2021.

Twelve of the 24 guidelines were described as living guidelines or contained statements with regard to maintenance of guidance statements.<sup>(2, 13, 14, 16, 21-23, 29, 31, 33, 34, 40)</sup> Five guidelines<sup>(30, 32, 36, 37, 39)</sup> were described as interim guidelines under review with updates due, of which one reported the expiry date of the interim guidance.<sup>(39)</sup> One guideline<sup>(33)</sup> (which is valid until 31 August 2023) is currently under revision as of 17 August 2022. See Table 3.1.

**Table 3.1 Summary of the included guidelines and or models of care**

| <b>Title</b>  | <b>International, national or regional</b>                        | <b>Adapted from a previous guideline</b>   | <b>Last updated</b>                        | <b>Recommendations on documented literature searches and expert consensus</b> |
|---|---|--|--|---|
| <b>Endorsing organisation (Country)</b>   | <b>Intended setting</b>   |  | <b>Most recent literature search</b>       |   |
| <b>First published</b>  | <b>General long COVID or specific sequelae</b>                    |  |  |   |
| Clinical rehabilitation guideline for people with long COVID (coronavirus disease) in Aotearoa New Zealand <sup>(28)</sup><br><br>Ministry of Health (New Zealand)<br><br>16 September 2022   | National<br><br>From primary care to acute<br><br>General         | This guideline was informed by guidelines from CDC, <sup>(37)</sup> NICE <sup>(2)</sup> and a UK panel of primary and secondary care practitioners <sup>(27)</sup> | 16 September 2022*<br><br>Not applicable   | Expert consensus  |
| Clinical management of COVID-19: living guideline <sup>(14)</sup><br><br>World Health Organization (International)<br><br>15 September 2022   | International<br><br>Not specified<br><br>General                 | Not reported   | 15 September 2022<br><br>24 September 2021 | Literature search and expert consensus  |
| Post-COVID-19 Conditions in Children and Adolescents <sup>(39)</sup><br><br>American Academy of Pediatrics (US)<br><br>28 July 2021   | National<br><br>Primary care<br><br>General                       | Partially adapted from CDC <sup>(37)</sup>   | 2 September 2022<br><br>Not reported       | Not reported  |
| Multi-disciplinary collaborative consensus guidance statement on the assessment and treatment of cardiovascular complications in patients with post-acute sequelae of SARS-CoV-2 infection <sup>(22)</sup><br><br>American Academy of Physical Medicine and Rehabilitation (US) (AAPMRd)<br><br>7 June 2022 | National<br><br>Not specified<br><br>Cardiovascular complications | Not reported   | 7 June 2022<br><br>May 2021                | Literature search and expert consensus  |

| <b>Title</b><br><b>Endorsing organisation (Country)</b><br><b>First published</b>  | <b>International, national or regional</b><br><b>Intended setting</b><br><b>General long COVID or specific sequelae</b> | <b>Adapted from a previous guideline</b>   | <b>Last updated</b><br><b>Most recent literature search</b> | <b>Recommendations on documented literature searches and expert consensus</b> |
|--|---|--|---|---|
| Australian Guidelines for the clinical care of people with COVID-19 <sup>(13)</sup><br><br>Australian National COVID-19 Clinical Evidence Taskforce (Australia)<br><br>8 May 2022  | National<br><br>General practice, community health, rehabilitation programmes and post-COVID-19 clinics<br><br>General  | Partially adapted CDC, <sup>(37)</sup> NICE, <sup>(2)</sup> RACGP, <sup>(24)</sup> NSW <sup>(40)</sup> and WHO <sup>(14)</sup> | 16 September 2022*<br><br>26 August 2022                    | Literature search and expert consensus  |
| Caring for patients with post-COVID-19 conditions <sup>(24)</sup><br><br>Royal Australian College of General Practitioners (Australia)<br><br>5 May 2022   | National<br><br>Primary care<br><br>General   | Not reported   | 5 May 2022<br><br>Not applicable                            | Not reported  |
| Expert Consensus Decision Pathway on Cardiovascular Sequelae of COVID-19 in Adults: Myocarditis and Other Myocardial Involvement, Post-Acute Sequelae of SARS-CoV-2 Infection, and Return to Play <sup>(42)</sup><br><br>American College of Cardiology (US)<br><br>3 May 2022 | National<br><br>Not specified<br><br>Cardiovascular sequelae  | Not reported   | Has not been updated<br><br>Not reported                    | Expert consensus  |



| Title<br>Endorsing organisation (Country)<br>First published   | International, national or regional<br>Intended setting<br>General long COVID or specific sequelae | Adapted from a previous guideline  | Last updated<br>Most recent literature search | Recommendations on documented literature searches and expert consensus |
|--|--|--|---|--|
| Italian intersociety consensus on management of long COVID in children <sup>(35)</sup><br>Italian Society of Pediatrics (Italy)<br>9 March 2022  | National<br>Primary care<br>General  | Not reported   | Has not been updated<br>15 November 2021      | Literature search  |
| Rapid guidelines for assessment and management of long COVID <sup>(21)</sup><br>European Society of Clinical Microbiology and Infectious Diseases (Europe)<br>17 February 2022   | International<br>Not specified<br>General  | Partially adapted from CDC, <sup>(37)</sup> NICE, <sup>(2)</sup> and WHO <sup>(14)</sup> | Has not been updated<br>31 December 2021      | Literature search and expert consensus                                 |
| Multi-disciplinary collaborative consensus guidance statement on the assessment and treatment of cognitive symptoms in patients with post-acute sequelae of SARS-CoV-2 infection <sup>(34)</sup><br>American Academy of Physical Medicine and Rehabilitation (US) (AAPMRa)<br>13 December 2021 | National<br>Not specified<br>Cognitive symptoms  | Not reported   | 13 December 2021<br>May 2021                  | Literature search and expert consensus                                 |

| Title<br>Endorsing organisation (Country)<br>First published  | International, national or regional<br>Intended setting<br>General long COVID or specific sequelae | Adapted from a previous guideline  | Last updated<br>Most recent literature search   | Recommendations on documented literature searches and expert consensus |
|---|--|--|---|--|
| <p>Multi-disciplinary collaborative consensus guidance statement on the assessment and treatment of breathing discomfort and respiratory sequelae in patients with post-acute sequelae of SARS-CoV-2 infection<sup>(29)</sup></p> <p>American Academy of Physical Medicine and Rehabilitation (US) (AAPMRc)</p> <p>13 December 2021</p> | <p>National</p> <p>Not specified</p> <p>Breathing discomfort and respiratory sequelae</p>          | <p>Not reported</p>  | <p>Has not been updated</p> <p>May 2021</p>     | <p>Literature search and expert consensus</p>                          |
| <p>Neurological manifestations of post-COVID-19 syndrome S1-guideline of the German society of neurology<sup>(33)</sup></p> <p>German Neurological Society (Germany)</p> <p>December 2021</p>   | <p>National</p> <p>Not specified</p> <p>Neurological manifestations</p>                            | <p>Not reported</p>  | <p>Has not been updated</p> <p>Not reported</p> | <p>Expert consensus</p>  |
| <p>Management of post-acute COVID-19 patients in geriatric rehabilitation<sup>(23)</sup></p> <p>European Geriatric Medicine Society (Europe)</p> <p>20 November 2021</p>  | <p>International</p> <p>Not specified</p> <p>General</p>   | <p>Adapted from the Dutch Association of Elderly Care Physicians and Social Geriatricians (Verenso)<sup>(43, 44)</sup></p> | <p>Has not been updated</p> <p>Not reported</p> | <p>Expert consensus</p>  |

| <b>Title</b><br><b>Endorsing organisation (Country)</b><br><b>First published</b>  | <b>International, national or regional</b><br><b>Intended setting</b><br><b>General long COVID or specific sequelae</b> | <b>Adapted from a previous guideline</b>                           | <b>Last updated</b><br><b>Most recent literature search</b>   | <b>Recommendations on documented literature searches and expert consensus</b> |
|--|---|--|---|---|
| Recommendations for the recognition, diagnosis, and management of long COVID: a Delphi study <sup>(27)</sup><br><br>No official endorsing organisation (UK)<br><br>28 October 2021 | National<br><br>General practice and long COVID clinical services<br><br>General  | Not reported   | Has not been updated<br><br>Informed by NIRH living review (last updated 16 May 2021) <sup>(45)</sup> | Expert consensus  |
| Post COVID-19 Condition: Guidance for Primary Care <sup>(26)</sup><br><br>Ontario Health, Government of Ontario (Canada)<br><br>December 2021                                      | Regional<br><br>Not specified<br><br>General  | Partially adapted from CDC <sup>(37)</sup>                         | Not reported<br><br>Not applicable  | Expert consensus  |
| Approach to assessment and management of long-term COVID-19 symptoms in primary care <sup>(38)</sup><br><br>British Columbia Ministry of Health (Canada)<br><br>5 August 2021      | Regional<br><br>Primary care<br><br>General   | Partially adapted from CDC <sup>(37)</sup> and NICE <sup>(2)</sup> | Has not been updated<br><br>Not reported  | Expert consensus  |

| <b>Title</b><br><b>Endorsing organisation (Country)</b><br><b>First published</b>  | <b>International, national or regional</b><br><b>Intended setting</b><br><b>General long COVID or specific sequelae</b> | <b>Adapted from a previous guideline</b>                                | <b>Last updated</b><br><b>Most recent literature search</b> | <b>Recommendations on documented literature searches and expert consensus</b> |
|--|---|---|---|---|
| <p>Multidisciplinary collaborative consensus guidance statement on the assessment and treatment of fatigue in post acute sequelae of SARS-CoV-2 infection patients<sup>(31)</sup></p> <p>American Academy of Physical Medicine and Rehabilitation (US) (AAPMRb)</p> <p>4 August 2021</p> | <p>National</p> <p>Not specified</p> <p>Fatigue</p>   | <p>Not reported</p>   | <p>Has not been updated</p> <p>May 2021</p>                 | <p>Literature search and expert consensus</p>                                 |
| <p>Interim guidance on Long-COVID management principles<sup>(30)</sup></p> <p>Istituto Superiore di Sanita (Italy)</p> <p>1 July 2021</p>  | <p>National</p> <p>Primary care and acute settings</p> <p>General</p>   | <p>Partially adapted from NICE<sup>(2)</sup> and WHO<sup>(14)</sup></p> | <p>Has not been updated</p> <p>Not reported</p>             | <p>Expert consensus</p>   |
| <p>Interim Guidance on Evaluating and Caring for Patients with Post-COVID Conditions<sup>(37)</sup></p> <p>Center for Disease Control (US)</p> <p>14 June 2021</p>   | <p>National</p> <p>Not specified</p> <p>General</p>   | <p>Not reported</p>   | <p>22 September 2022*</p> <p>Not reported</p>               | <p>Expert consensus</p>   |

| <b>Title</b><br><b>Endorsing organisation (Country)</b><br><b>First published</b>   | <b>International, national or regional</b><br><b>Intended setting</b><br><b>General long COVID or specific sequelae</b> | <b>Adapted from a previous guideline</b>   | <b>Last updated</b><br><b>Most recent literature search</b> | <b>Recommendations on documented literature searches and expert consensus</b> |
|---|---|--|---|---|
| Swiss Recommendations for the Follow-Up and Treatment of Pulmonary Long COVID <sup>(32)</sup><br><br>Swiss COVID Lung Study Group and the Swiss Society of Pulmonology (Switzerland)<br><br>4 June 2021   | National<br><br>Not specified<br><br>Pulmonary  | Not reported                               | Has not been updated<br><br>Not applicable                  | Expert consensus  |
| Clinical practice guide for assessment and management of adults with post-acute sequelae of COVID-19<br>Guidance for NSW health clinicians <sup>(40)</sup><br><br>Agency for Clinical Innovation, New South Wales government (Australia)<br><br>31 May 2022 | Regional<br><br>From primary care to acute<br><br>General   | Not reported                               | 14 July 2022<br><br>Not reported                            | Expert consensus  |
| Long Covid-19: proposed primary care clinical guidelines for diagnosis and disease management <sup>(16)</sup><br><br>Catalan Society of Family and Community Medicine (Spain)<br><br>20 April 2021  | National<br><br>Primary care (non-hospitalised patients)<br><br>General   | Partially adapted from NICE <sup>(2)</sup> | Has not been updated<br><br>13 January 2021                 | Literature search and expert consensus  |

| Title  | International, national or regional                                | Adapted from a previous guideline          | Last updated                             | Recommendations on documented literature searches and expert consensus |
|--|--|--|--|--|
| Endorsing organisation (Country)   | Intended setting   |  | Most recent literature search            |  |
| First published  | General long COVID or specific sequelae                            |  |  |  |
| Interim COVID-19 Clinical Management Guidelines <sup>(36)</sup><br><br>COVID-19 Clinical Management Committee (Singapore)<br><br>15 April 2021           | National<br><br>Not specified<br><br>General                       | Not reported                               | Has not been updated<br><br>Not reported | Not reported   |
| Long COVID-19: A Primer for Cardiovascular Health Professionals <sup>(25)</sup><br><br>The Canadian Cardiovascular Society (Canada)<br><br>12 March 2021 | National<br><br>Not specified<br><br>Cardiac-related complications | Partially adapted from NICE <sup>(2)</sup> | Has not been updated<br><br>Not reported | Expert consensus   |
| COVID-19 rapid guideline: managing the long-term effects of COVID-19 <sup>(2)</sup><br><br>NICE, RCGP and SIGN (UK)<br><br>18 December 2020              | National<br><br>All healthcare settings<br><br>General             | Not reported                               | 19 May 2022*<br><br>21 July 2022         | Literature search and expert consensus                                 |
| Provincial Adult long COVID pathway <sup>(41)</sup><br><br>Alberta Health Services (Canada)<br><br>September 2020  | Regional<br><br>Primary care and acute settings<br><br>General     | Not reported                               | March 2021<br><br>Not reported           | Literature search and expert consensus                                 |

**Key:** NICE - National Institute for Health and Care Excellence; RACGP - Royal Australian College of General Practitioners; RCGP - Royal College of General Practitioners; SIGN - Scottish Intercollegiate Guidelines Network.

\*guideline has been updated since the searches were conducted on 22 September 2022.

### 3.3 Quality appraisal

An overview of the methodological quality of the 24 included guidelines<sup>(2, 13, 14, 16, 21-40)</sup> and two models of care,<sup>(41, 42)</sup> as assessed by the AGREE-GRS tool, is provided in Table 3.2 and summarised below. The four domain scores (1=lowest quality, 7=highest quality) are presented for each guideline in accordance with the AGREE-GRS manual.<sup>(20)</sup> To aid in the quality appraisal process, we included additional considerations to each domain (presented in Appendix 5). The included guidelines and or models of care varied in terms of quality. Three of the 24 guidelines were deemed to be of consistently high quality across all four domains and in terms of the overall quality assessment.<sup>(2, 13, 14)</sup>

#### *Domain 1: Process of Development*

The guidelines produced by NICE,<sup>(2)</sup> WHO,<sup>(14)</sup> Australian National COVID-19 Clinical Evidence Taskforce<sup>(13)</sup> and ESCMID<sup>(21)</sup> achieved the highest assessment scores (100%) in terms of describing the scope and purpose of their respective guidelines. The 20 remaining guidelines and two models of care did not provide full descriptions of how the evidence base was developed, explicit links between the evidence and recommendations, stakeholders involved, or planned updates.

#### *Domain 2: Presentation Style*

The guidelines produced by NICE,<sup>(2)</sup> WHO,<sup>(14)</sup> Australian National COVID-19 Clinical Evidence Taskforce<sup>(13)</sup> and ESCMID<sup>(21)</sup> achieved the highest assessment scores (100%) with regards to clarity of presentation and organisation. A lack of organisation in terms of the location of recommendations within the narrative text led to the remaining 20 guidelines and two models of care receiving lower scores for this domain.

#### *Domain 3: Completeness of Reporting*

Nine guidelines (from NICE,<sup>(2)</sup> WHO,<sup>(14)</sup> Australian National COVID-19 Clinical Evidence Taskforce,<sup>(13)</sup> ESCMID,<sup>(21)</sup> Swiss COVID Lung Study Group and the Swiss Society of Pulmonology,<sup>(32)</sup> AAPMRa,<sup>(34)</sup> AAPMRb,<sup>(31)</sup> AAPMRc<sup>(29)</sup> and AAPMRd<sup>(22)</sup>) and the model of care from Alberta, Canada,<sup>(41)</sup> achieved high assessment scores (71% to 100%) in terms of completeness of reporting. The remaining 15 guidelines and one model of care achieved low scores, with areas of poor reporting within the domain including poorly described or a complete absence of a decision-making framework for formulating recommendations.

#### *Domain 4: Clinical Validity*

The guidelines from NICE,<sup>(2)</sup> WHO,<sup>(14)</sup> Australian National COVID-19 Clinical Evidence Taskforce,<sup>(13)</sup> ESCMID,<sup>(21)</sup> New Zealand Ministry of Health,<sup>(28)</sup> AAPMRa,<sup>(34)</sup> AAPMRb,<sup>(31)</sup> AAPMRc<sup>(29)</sup> and AAPMRd<sup>(22)</sup> and the model of care from Alberta, Canada<sup>(41)</sup> achieved high assessment scores for clinical validity (71% to 93%). Areas of poor reporting across the remaining 15 guidelines and one model of care included the criteria used to select the evidence (inclusion and or exclusion criteria such as population and disease stage), search dates of evidence sources underpinning recommendations, consideration of benefits and harms in formulating recommendations, and the external review of recommendations.

*Overall Assessment (overall quality, use in practice, use in professional decisions)*

The overall assessment takes consideration of scores for three criteria: the overall quality, use in practice, and use in professional decisions score. Guidelines from NICE<sup>(2)</sup> and WHO<sup>(36)</sup> had scores of 100% in each of these three criteria. Guidelines from the Australian National COVID-19 Clinical Evidence Taskforce,<sup>(13)</sup> CAMFiC,<sup>(16)</sup> ESCMID,<sup>(21)</sup> Swiss COVID Lung Study Group and the Swiss Society of Pulmonology<sup>(32)</sup> AAPMRa,<sup>(34)</sup> AAPMRb,<sup>(31)</sup> AAPMRc<sup>(29)</sup> and AAPMRd<sup>(22)</sup> and the model of care from Alberta, Canada<sup>(41)</sup> also achieved high scores with scores of greater than 70% in each of these three criteria.



**Table 3.2 Quality of included guidelines by the AGREE GRS domains**

| Guideline   | Domain 1:<br>Process of development | Domain 2:<br>Presentation style | Domain 3:<br>Completeness of reporting | Domain 4:<br>Clinical validity | Overall Assessment |                               |                               |
|---|-------------------------------------|---------------------------------|--|--------------------------------|--------------------|-------------------------------|-------------------------------|
|   |                                     |                                 |  |                                | Overall quality    | Recommend for use in practice | Use in professional decisions |
| NICE <sup>(2)</sup>                                   | 100%                                | 100%                            | 100%                                   | 93%                            | 100%               | 100%                          | 100%                          |
| WHO <sup>(14)</sup>                                   | 100%                                | 100%                            | 100%                                   | 86%                            | 100%               | 100%                          | 100%                          |
| Australia <sup>(13)</sup>                             | 100%                                | 100%                            | 93%                                    | 86%                            | 93%                | 93%                           | 93%                           |
| Alberta, Canada <sup>(41)</sup>                       | 71%                                 | 86%                             | 100%                                   | 86%                            | 86%                | 71%                           | 71%                           |
| ESCMID <sup>(21)</sup>                                | 100%                                | 100%                            | 71%                                    | 71%                            | 86%                | 86%                           | 86%                           |
| AAPMRa (Cognitive Symptoms) <sup>(34)</sup>           | 86%                                 | 86%                             | 86%                                    | 71%                            | 79%                | 79%                           | 79%                           |
| AAPMRb (Fatigue) <sup>(31)</sup>                      | 86%                                 | 86%                             | 79%                                    | 71%                            | 79%                | 79%                           | 79%                           |
| AAPMRc (Breathing Discomfort) <sup>(29)</sup>         | 86%                                 | 86%                             | 79%                                    | 71%                            | 79%                | 79%                           | 79%                           |
| AAPMRd (Cardiovascular Complications) <sup>(22)</sup> | 86%                                 | 86%                             | 79%                                    | 79%                            | 79%                | 79%                           | 79%                           |
| CAMFiC <sup>(16)</sup>                                | 71%                                 | 64%                             | 50%                                    | 64%                            | 71%                | 71%                           | 71%                           |
| Swiss (Pulmonary Symptoms) <sup>(32)</sup>            | 86%                                 | 86%                             | 79%                                    | 64%                            | 71%                | 71%                           | 71%                           |
| GSN (Neurological Manifestations) <sup>(33)</sup>     | 57%                                 | 57%                             | 43%                                    | 57%                            | 57%                | 57%                           | 57%                           |
| Singapore <sup>(36)</sup>                             | 14%                                 | 86%                             | 43%                                    | 14%                            | 57%                | 57%                           | 57%                           |
| UK panel of experts <sup>(27)</sup>                   | 57%                                 | 86%                             | 50%                                    | 43%                            | 57%                | 57%                           | 57%                           |
| New Zealand <sup>(28)</sup>                           | 29%                                 | 71%                             | 14%                                    | 71%                            | 50%                | 43%                           | 43%                           |
| ACC (Cardiovascular Complications) <sup>(42)</sup>    | 57%                                 | 36%                             | 36%                                    | 50%                            | 43%                | 43%                           | 43%                           |
| EuGMS <sup>(23)</sup>                                 | 57%                                 | 64%                             | 29%                                    | 43%                            | 43%                | 43%                           | 50%                           |
| British Columbia, Canada <sup>(38)</sup>              | 43%                                 | 64%                             | 21%                                    | 29%                            | 43%                | 29%                           | 29%                           |
| ISS <sup>(30)</sup>                                   | 43%                                 | 50%                             | 14%                                    | 21%                            | 43%                | 43%                           | 43%                           |
| RACGP <sup>(24)</sup>                                 | 29%                                 | 79%                             | 14%                                    | 50%                            | 43%                | 43%                           | 43%                           |
| CDC <sup>(37)</sup>                                   | 29%                                 | 57%                             | 21%                                    | 29%                            | 36%                | 36%                           | 36%                           |
| ISP <sup>(35)</sup>                                   | 71%                                 | 79%                             | 43%                                    | 29%                            | 36%                | 36%                           | 36%                           |
| New South Wales, Australia <sup>(40)</sup>            | 71%                                 | 50%                             | 14%                                    | 36%                            | 36%                | 29%                           | 21%                           |
| AAP <sup>(39)</sup>                                   | 29%                                 | 43%                             | 21%                                    | 36%                            | 29%                | 29%                           | 29%                           |
| CCS (Cardiovascular Complications) <sup>(25)</sup>    | 14%                                 | 43%                             | 21%                                    | 29%                            | 29%                | 29%                           | 29%                           |
| Ontario, Canada <sup>(26)</sup>                       | 43%                                 | 57%                             | 29%                                    | 21%                            | 29%                | 29%                           | 29%                           |

**Key:** AAP - American Academy of Pediatrics; AAPMR - American Academy of Physical Medicine and Rehabilitation; ACC - American College of Cardiology; CAMFiC - Catalan Society of Family and Community Medicine; CCS - Canadian Cardiovascular Society; CDC - Centres for Disease Control and Prevention; ESCMID - European Society of Clinical Microbiology and Infectious Diseases; EuGMS - European Geriatric Medicine Society; GNS - German Neurological Society; ISP - Italian Society of Pediatrics; ISS - Istituto Superiore di Sanita; NICE – National Institute for Health and Care Excellence; RACGP - Royal Australian College of General Practitioners; RCGP - Royal College of General Practitioners; SIGN - Scottish Intercollegiate Guidelines Network; WHO – World Health Organization.

### **3.4 Definitions of long COVID**

Differences were observed in the definition of long COVID across the included guidelines and or models of care; these differences predominantly related to the period of time following acute COVID-19, during which clinical symptoms could be attributed to long COVID. A detailed overview of the definitions used by the clinical guidelines and or models of care included within this review is provided in Appendix 3 and Appendix 4.

Across the guidelines and models of care, a range of terms were identified that were considered synonymous with 'long COVID'. These included post-acute sequelae of SARS-CoV-2 infection (PASC), post-COVID condition, persistent or ongoing symptomatic COVID-19 disease, post-COVID syndrome and persistent post-acute COVID-19 symptoms. However, the importance of clinical evaluation and supportive care during the initial 4 to 12 weeks after acute COVID-19 was frequently emphasised across the guidelines and or models of care. As such, for review, the aforementioned terms are considered synonyms of long COVID.

Fourteen of the 24 guidelines<sup>(2, 16, 22, 25-27, 29-34, 37, 39)</sup> and both models of care<sup>(41, 42)</sup> defined long COVID as symptoms that persist for four or more weeks following acute COVID-19. Four of these guidelines<sup>(2, 16, 25, 33)</sup> used the NICE clinical case definition where long COVID refers to both ongoing symptomatic COVID-19 (from 4 to 12 weeks) and post-COVID-19 syndrome (12 weeks or more).

Two guidelines<sup>(14, 40)</sup> used the WHO definition of long COVID (referred to as post-COVID-19 condition), defined as the continuation or development of new symptoms three months after the initial SARS-CoV-2 infection, with these symptoms lasting for at least two months with no other explanation. Five guidelines<sup>(13, 21, 28, 35, 38)</sup> defined long COVID as symptoms persisting for 12 weeks or more post-infection, of which one (Australian National COVID-19 Clinical Evidence Taskforce)<sup>(13)</sup> included the caveat that long COVID (again referred to as post-COVID condition) may be considered where the possibility of an alternative diagnosis is also being assessed.

The RACGP guideline,<sup>(24)</sup> referenced the NICE and WHO definitions. The EuGMS guideline<sup>(23)</sup> applied a definition of post-acute COVID-19 to patients who have survived the acute phase of COVID-19 at home or in a hospital and are currently recovering. The Singapore guideline<sup>(36)</sup> referenced persistent post-acute COVID-19 symptoms but did not apply a timeframe to the definition.

In addition to a general definition of long COVID, the ACC model of care<sup>(42)</sup> included two definitions specific to cardiovascular sequelae of long COVID. Firstly, PASC-related cardiovascular disease refers to a broad group of cardiovascular conditions that manifest for four or more weeks after SARS-CoV-2 infection (for example,

myocarditis, pericarditis, thromboembolism and arrhythmia). Secondly, PASC-related cardiovascular syndrome is a heterogeneous disorder that includes a wide range of cardiovascular symptoms without objective evidence of cardiovascular disease using standard diagnostic tests.

### **3.5 Recommendations of interest**

Three topics of interest were extracted from the included guidelines and or models of care:

- recommendations for the diagnosis of long COVID
- recommendations for the treatment and or management of long COVID
- and recommendations for service planning for long COVID.

A matrix of recommendations included by the guidelines and or models of care in this review is provided in Table 3.3, with a detailed overview of the recommendations provided in Appendix 3 and Appendix 4.

Ten of the 24 guidelines<sup>(2, 13, 14, 16, 21, 22, 29, 31, 32, 34)</sup> and one of the two models of care<sup>(41)</sup> achieved an AGREE-GRS assessment score of greater than 70% for overall quality. Therefore, we refer to these as higher quality guidelines and or models of care. The narrative summary of the recommendations of interest will focus on these higher quality guidelines and model of care, as well as those that were specific to population sub-groups such as older adults and paediatrics.

#### **3.5.1 Recommendations on diagnosis of long COVID**

Nine guidelines<sup>(2, 13, 16, 21, 22, 29, 31, 32, 34)</sup> and one model of care<sup>(41)</sup> (deemed to be of higher quality) contained recommendations concerning the diagnosis of long COVID. The WHO<sup>(14)</sup> guideline focused on management and service planning for long COVID rather than diagnosis.

Consensus recommendations (that is, when there is insufficient evidence for an evidence-based recommendation, but the guideline development group still regards it as important to give a recommendation) and conditional recommendations (that is, when the benefits of the intervention are greater than the disadvantages, but when this is not substantiated by strong evidence) were common across the nine guidelines<sup>(2, 13, 16, 21, 22, 29, 31, 34)</sup> and one model of care.<sup>(41)</sup> There was an emphasis on the broad and fluctuating range of symptoms associated with long COVID across four of the six higher quality guidelines and model of care that focused on general long COVID.<sup>(2, 14, 16, 21)</sup> One of these guidelines<sup>(21)</sup> highlighted that there was insufficient evidence for or against the use of specific diagnostic tests for the long COVID symptoms addressed in their review. Eight guidelines<sup>(2, 13, 16, 21, 22, 29, 31, 34)</sup> referenced the need to identify potential causes or conditions that may reasonably

explain, be related to, or exacerbate the symptoms, with the potential for a diagnosis of long COVID once alternative diagnoses have been ruled out.

In terms of who should be assessed for long COVID and when, nine guidelines<sup>(2, 13, 16, 21, 22, 29, 31, 34)</sup> and one model of care<sup>(41)</sup> recommended that further assessment should be considered if the patient reports experiencing new or persistent symptoms four or more weeks following confirmed or likely SARS-CoV-2 infection. For patients who were hospitalised during the acute COVID-19 phase, NICE guidelines recommended that a healthcare professional in secondary care should offer a follow-up consultation six weeks after discharge to check for new or ongoing symptoms or complications.<sup>(2)</sup> The Swiss guideline<sup>(32)</sup> recommended that those who were hospitalised with COVID-19, and those with ongoing symptomatic COVID-19, undergo pulmonary assessment within 12 weeks. Similarly, the Alberta, Canada model of care<sup>(41)</sup> recommended screening hospitalised patients with COVID-19 for rehabilitation needs at each transition of care, that is, between hospital and community care.

The guidelines from NICE<sup>(2)</sup> and the Australian National COVID-19 Clinical Evidence Taskforce<sup>(13)</sup> and the model of care from Alberta, Canada<sup>(17)</sup> highlighted the need for a holistic, person-centred approach to assessment for those with ongoing symptomatic COVID-19 or suspected long COVID. These guidelines<sup>(2, 13)</sup> and the guideline from the AAPMRd<sup>(22)</sup> recommended the facilitation of shared decision-making by offering information on the symptoms experienced by the patient and potential management options.

Eight guidelines<sup>(2, 13, 16, 21, 22, 29, 31, 34)</sup> and one model of care<sup>(41)</sup> recommended assessment that includes a comprehensive assessment of the patient's clinical history and their medications, an examination of their physical, cognitive, psychological and psychiatric symptoms, as well as functional abilities and consideration of the impact of the reported symptoms on their quality of life. Further recommendations for the initial assessment included documenting the details of the acute illness and the use of a screening questionnaire to capture the patient's symptoms.<sup>(2, 13, 41)</sup> Six guidelines recommended supporting access to assessment for those who may have difficulty accessing services due to health inequities.<sup>(2, 13, 22, 29, 31, 34)</sup> Three guidelines highlighted 'red flag' symptoms, (such as severe, new onset, or worsening breathlessness or hypoxia, syncope, unexplained chest pain, palpitations or arrhythmias, new delirium, or focal neurological signs or symptoms), that require urgent referral to acute services.<sup>(2, 13, 16)</sup>

Symptom-based assessment was recommended across nine of the guidelines<sup>(2, 13, 16, 21, 22, 29, 31, 34)</sup> and one model of care,<sup>(41)</sup> with assessments and tests that are necessary for determining care tailored to the symptoms reported by the individual.

Similarly, decisions regarding blood and laboratory tests should be guided by the patient's symptoms.<sup>(2, 13, 16, 21, 22, 31, 34)</sup>

The guidelines from NICE<sup>(2)</sup> and the Australian National COVID-19 Clinical Evidence Taskforce<sup>(13)</sup> provided specific recommendations for orthostatic intolerance or postural symptoms of long COVID, such as palpitations and dizziness when standing. These recommendations included lying and standing blood pressure and heart rate recordings (3-minute active stand test for orthostatic hypotension, or 10 minutes if postural tachycardia syndrome is suspected, or other forms of orthostatic intolerance). Six guidelines<sup>(2, 13, 16, 21, 22, 32)</sup> recommended respiratory functional tests (for example, plethysmography, diffusion capacity measurement, blood gases analysis and exercise tests) and chest radiography if the person has persistent respiratory symptoms and it is clinically indicated. A time frame of 12 weeks post-COVID-19 for chest radiography of symptomatic patients was recommended by four of the guidelines.<sup>(2, 13, 21, 32)</sup> Pulmonary function testing was recommended at 8 to 12 weeks for patients with persistent shortness of breath.<sup>(21, 29)</sup> For patients with cardiovascular symptoms, electrocardiogram, echocardiogram, ambulatory cardiac monitoring and cardiac imaging were recommended by three guidelines on a case-by-case basis.<sup>(16, 21, 22)</sup>

Two guidelines (from the CAMFiC<sup>(16)</sup> and the AAPMRb<sup>(31)</sup>) contained recommendations related to the assessment of fatigue. These guidelines recommended taking a full clinical history of fatigue symptoms and accompanying signs, psychological factors, related medications, history of substance abuse, sleep disorders, exposure to toxins, and changes in quality of life. Assessment of fatigue patterns throughout the patient's normal day was recommended to inform activity advice as well as an assessment of physical functioning and endurance.<sup>(31)</sup>

Two guidelines (from NICE<sup>(2)</sup> and the AAPMRa<sup>(34)</sup>) contained recommendations for the assessment of cognitive dysfunction for those reporting subjective cognitive impairment following acute COVID-19. Similar to recommendations for symptoms of fatigue, assessment of cognitive dysfunction following acute COVID-19 should include a full patient history related to preexisting conditions, related medications and supplements, presence of sleep disorders, psychological factors, and changes to activities of daily living and quality of life. The guidelines recommend that patient history be validated through another source, such as the patient's primary care doctor, family caregiver, or close contact, as available. Use of a validated cognitive assessment screening tool is recommended for those reporting new cognitive dysfunction,<sup>(2, 34)</sup> followed by a comprehensive neuropsychological assessment by a trained professional where cognitive impairment is indicated.<sup>(34)</sup>

The AAPMRa Cognitive Symptoms guideline<sup>(34)</sup> noted a lack of consistent evidence to indicate when a diagnosis of cognitive dysfunction during the acute or post-acute

COVID-19 phase should occur, as COVID-19-related cognitive symptoms may have delayed onset, and may fluctuate or be continually present from the acute infection phase. This guideline<sup>(34)</sup> also recommended a thorough neurological examination to identify focal neurological deficits in patients and consideration of neuroimaging for those patients with new or worsening focal neurological deficits (this includes new or worsening cognitive symptoms).

For patients presenting with persistent headache, the CAMFiC guideline<sup>(16)</sup> recommended temporomandibular joint examination, cranial palpation and a complete neurological assessment. For patients aged over 50 years, the CAMFiC guideline<sup>(16)</sup> further recommended the assessment of blood pressure, temporal artery inspection and palpation.

### **Recommendations on diagnosis of long COVID in specific sub-groups**

Guidelines from the ISP,<sup>(35)</sup> AAP<sup>(39)</sup> and New Zealand Ministry of Health<sup>(28)</sup> provided recommendations for the diagnosis of long COVID in paediatric populations. The EuGMS<sup>(23)</sup> guideline provided recommendations for rehabilitation of older adult populations post-COVID. Of note, these guidelines were not deemed to be higher quality due to an overall quality assessment score of 70% or lower.

The ISP<sup>(35)</sup> guideline recommended evaluation of symptoms suggestive of long COVID near the end of the acute phase of the disease, that is, between 4 and 12 weeks following COVID-19 infection. A diagnosis of long COVID should be considered with presentations of symptoms such as persistent headache and fatigue, sleep disturbance, difficulty in concentrating, abdominal pain, myalgia or arthralgia, persistent chest pain, stomach pain, diarrhea, heart palpitations, and skin lesions.

Similar to adult long COVID guidelines, the AAP<sup>(39)</sup> guideline recommended ruling out 'red flag' cardiac or neurological symptoms in children and adolescents presenting with fatigue or headache, respectively. The New Zealand Ministry of Health<sup>(28)</sup> guideline also recommended consideration of 'red flag' symptoms in children and young adults presenting with ongoing symptoms of COVID-19. These 'red flag' symptoms included pulmonary embolism, myocarditis, cardiomyopathy, venous thromboembolism, renal failure, type 1 diabetes mellitus, paediatric inflammatory syndrome, functional neurological disorder, and paediatric acute-onset neuropsychiatric syndrome. The AAP guideline<sup>(39)</sup> recommended chest imaging for patients who experienced pulmonary abnormalities during the acute COVID-19 phase and continue to experience persistent symptoms. Moreover, pulmonary function testing was recommended for children aged six years and older with persistent respiratory symptoms. Age-specific neurodevelopmental history and evaluation is recommended for neurodevelopmental impairment. The AAP guideline acknowledged the challenges in diagnosing smell and taste impairment in very young children but recommended further evaluation, nutrition optimisation, olfactory



testing, and potentially olfactory training for children with persistent anosmia. The AAP<sup>(39)</sup> guideline recommended consideration of a conservative approach to assessment for the 4 to 12 weeks following illness due to the harm that may arise from excessive testing. For symptoms persisting past 12 weeks, the AAP recommended additional diagnostic tests and or referral to a multidisciplinary paediatric long COVID clinic. Where a multidisciplinary paediatric long COVID clinic is not readily available, the AAP recommended referral to a paediatric subspecialist on the basis of the most problematic symptoms.

The EuGMS<sup>(23)</sup> guideline provided recommendations for rehabilitation of older adult populations post-COVID, this begins with a comprehensive geriatric assessment (CGA) to evaluate the frailty status, functional prognosis, trainability, cognition and motivation of the patient, with a specific focus on COVID-19-related complications and symptoms. The EuGMS guideline recommended shared decision-making regarding hospital discharge destination, and involvement of a caregiver (if applicable) in communications on rehabilitation planning and advanced care planning in the case of deterioration.

A detailed overview of recommendations for the diagnosis of long COVID from all 24 guidelines and two models of care included in this review are available in Appendix 3 and Appendix 4. This includes recommendations for assessment of additional symptoms such as cough, joint pain, myalgia, anosmia and or dysgeusia (that is, smell and taste disorders), and digestive symptoms.

### **3.5.2 Recommendations on treatment and or management of long COVID**

All ten guidelines<sup>(2, 13, 14, 16, 21, 22, 29, 31, 32, 34)</sup> and one model of care<sup>(41)</sup> that were deemed to be of higher quality and thus included in this narrative synthesis had recommendations concerning the management and or treatment of long COVID.

#### **General management and or treatment of long COVID**

Similar to the recommendations on the diagnosis of long COVID, consensus recommendations and conditional recommendations on the treatment and or management of long COVID were common across the ten guidelines<sup>(2, 13, 14, 16, 21, 22, 29, 31, 32, 34)</sup> and one model of care.<sup>(41)</sup>

Due to the uncertainty of the evidence, three guidelines<sup>(13, 14, 21)</sup> recommended treatment of certain symptoms of long COVID (for example, dyspnoea) with well-established clinical approaches through the use of existing guidelines and clinical expertise (such as, referral to pulmonology). One guideline<sup>(21)</sup> highlighted that there was insufficient evidence for or against treatment of long COVID symptoms addressed in their review. One guideline<sup>(13)</sup> explicitly recommended against the use

of emerging or unproven therapies that were not assessed in randomised trials with appropriate ethical approval. Two guidelines<sup>(2, 13, 41)</sup> and one model of care<sup>(39)</sup> highlighted the need for a holistic, person-centred approach to the management of long COVID symptoms. This included facilitation of shared decision-making to agree the level of support and rehabilitation needed for the individual. It was also recommended that consideration should be given to the impact symptoms may be having on their quality of life.<sup>(2)</sup>

General long COVID management recommendations included provision of information on self-management, sources of advice and support, and education and skills training on energy conservation techniques. The guidelines specified that these recommendations should be coupled with support from integrated and coordinated primary and community care, rehabilitation and mental health services, or referral to an integrated multidisciplinary service, depending on the clinical need and local pathways.<sup>(2, 14, 41)</sup> A multidisciplinary, personalised approach to rehabilitation was recommended by six guidelines<sup>(2, 16, 31, 34)</sup> and one model of care;<sup>(41)</sup> this included physical, psychological and psychiatric facets of management.

Three guidelines<sup>(2, 13, 14)</sup> and one model of care<sup>(41)</sup> recommended that clinical records and rehabilitation plans be shared in a timely manner between services and through multidisciplinary team meetings, either virtually or in-person. They also recommended that baseline measures and ongoing assessments (using standardised tools, where possible) be shared across services including when the individual is discharged from hospital. Two guidelines<sup>(2, 34)</sup> and one model of care<sup>(41)</sup> recommended that care is provided by the same healthcare professional or team, where possible, throughout the patient's journey.<sup>(2, 41)</sup> Frequent assessment of the impact of return to normal, daily activities (including school, work) was recommended to monitor flare-up of symptoms.<sup>(34, 41)</sup>

Three guidelines<sup>(2, 14, 29)</sup> recommended beginning rehabilitation by investigating symptoms that could affect the patient's ability to participate in rehabilitation, such as orthostatic intolerance and post-exertional symptom exacerbation (PESE). A shared decision-making approach was recommended for discussion and agreement of plans for discharge from rehabilitation; these plans should take into account the patient's preferences, goals and social support.<sup>(2)</sup> The Alberta, Canada model of care<sup>(41)</sup> recommended that comprehensive rehabilitation assessments of identified issues be completed at every level of care (through the use of cognitive, physical and psychological screening tools), where indicated, during acute care. Multi-system assessments (for example, cardiovascular and pulmonary systems) that build on results from initial screening tools were recommended, with priority assessments for those in the intensive care unit.



Four guidelines<sup>(13, 22, 31, 34)</sup> and one model of care<sup>(41)</sup> recommended monitoring and managing underlying medical conditions and lifestyle factors (such as smoking, alcohol use and physical activity) in patients with persistent symptoms following COVID-19. Six guidelines<sup>(2, 13, 22, 29, 31, 34)</sup> recommended additional support for those who may have difficulty accessing services due to health inequities or complex needs. Two guidelines<sup>(2, 14)</sup> recommended supporting individuals in discussions about a phased return to education and or employment.

### **Symptom specific management and or treatment**

Two guidelines (from the WHO<sup>(14)</sup> and the Australian National COVID-19 Clinical Evidence Taskforce<sup>(13)</sup>) contained specific recommendations for the management of PESE; this comprised a conservative rehabilitation plan in conjunction with physiotherapy for cautious initiation and pacing of activity or movement.

Two guidelines (from the WHO<sup>(14)</sup> and the CAMFiC<sup>(16)</sup>) provided specific recommendations for pain management, this included a combination of pain education, skills training on self-management strategies, and a prescription of short-term anti-inflammatory drugs; referral to a pain unit or rheumatology was also recommended. Three guidelines (from the WHO,<sup>(14)</sup> the AAPMRc<sup>(29)</sup> and Switzerland<sup>(32)</sup>) contained specific recommendations for management of breathing discomfort, this included a combination of education and skills training in self-management strategies, such as breathing exercises and, in the absence of PESE, personalised rehabilitation. Referral to pulmonology for evaluation and pulmonary rehabilitation was also recommended by these guidelines if applicable.

The Swiss guideline<sup>(32)</sup> recommended inhaled or systemic steroid treatment for patients who present with new obstructive lung disease following COVID-19. They further recommended inhaled steroids for those with persistent cough following COVID-19. For those presenting with interstitial abnormalities following exclusion of an active infection, the Swiss guideline<sup>(32)</sup> recommended evaluation to determine if the patient should receive a systemic steroid trial. Two guidelines (from the WHO<sup>(14)</sup> and the AAPMRb<sup>(31)</sup>) provided recommendations for management of fatigue. Treatment recommendations included a personalised, staged return to an activity programme, in the absence of PESE. Education and energy conservation strategies were also recommended in addition to healthy lifestyle education and treatment of underlying medical conditions that may be contributing to fatigue.

Two guidelines (from the WHO<sup>(14)</sup> and the AAPMRa<sup>(34)</sup>) contained recommendations for the management of cognitive dysfunction, such as referral to a specialist with expertise in formal cognitive assessment and rehabilitation, management of underlying medical conditions that may exacerbate symptoms, medication review in collaboration with primary care, and self-management strategies. Three guidelines<sup>(14, 16, 21)</sup> recommended olfactory training for the management of anosmia and or

dysgeusia (that is, smell and taste disorders) and referral to otolaryngology where applicable.

The AAPMRd guideline<sup>(22)</sup> contained management recommendations specific to cardiac complications. Recommendations comprised education relating to risk factor and lifestyle modifications, consultation with cardiology where applicable (for example, in the case of new or worsening cardiac symptoms), cardiac rehabilitation for eligible individuals, and staged return to sports performance for athletes. The ESCMID guideline<sup>(21)</sup> noted that while the evidence was insufficient to provide a recommendation for or against treatments for thromboprophylaxis, an individualised risk stratification of the risk for thrombotic events compared to haemorrhagic events could be performed. The guideline also advised extended anticoagulation prophylaxis for patients with a low risk of bleeding and an elevated risk for venous thromboembolism.<sup>(21)</sup>

### **Recommendations on treatment and management of long COVID in specific sub-groups**

Guidelines from the ISP,<sup>(35)</sup> NICE,<sup>(2)</sup> New Zealand Ministry of Health<sup>(28)</sup> and AAP<sup>(39)</sup> provided recommendations for the management and or treatment of long COVID in paediatric populations. With the exception of the guideline from NICE,<sup>(2)</sup> these guidelines were not deemed to be higher quality due to an overall quality assessment score of 70% or lower. The ISP<sup>(35)</sup> guideline recommended that primary care paediatricians assess all patients with a suspected or proven diagnosis of SARS-CoV-2 infection after four weeks to check for newly developed symptoms. This was similar to the NICE<sup>(2)</sup> guideline, where referral for specialist advice (that is, advice from a primary care paediatrician) from four weeks for children with ongoing symptomatic COVID-19 or post-COVID-19 syndrome was recommended. A further checkup by a primary care paediatrician was recommended 12 weeks following SARS-CoV-2 infection to assess the presence of and evaluate persistent symptoms.

The ISP<sup>(35)</sup> guideline recommended that children and adolescents with clear symptoms of mental stress be followed up by existing mental health services. The New Zealand Ministry of Health<sup>(28)</sup> guideline recommended energy conservation strategies (such as, pacing and flexible education formats) for children and young people with fatigue, provision of symptom-guided or paced return to sport for those with cardiac symptoms, and targeted psychological support for children and or young people who experienced fatigue-related frustration and difficulties with pacing. In addition, they recommended support for, and monitoring of, caregiver fatigue.

The AAP<sup>(39)</sup> guideline recommended referral to a neurodevelopmental neurologist, developmental and behavioural paediatrician, neuropsychologist, speech and

language therapist, psychologist, and or physiotherapist or occupational therapist for persistent cognitive and or neurodevelopmental symptom management.

For patients exhibiting PESE, the AAP<sup>(39)</sup> guideline recommended that a return to physical activity be closely monitored by a paediatrician or physiotherapist with specialised training or knowledge of PESE. For management of headaches, the AAP<sup>(39)</sup> guideline recommended monitoring and management of lifestyle factors in the first instance, followed by initiation of preventative medication if symptoms are severe enough to impede recovery.

Guidelines from the New Zealand Ministry of Health<sup>(28)</sup> and EuGMS<sup>(23)</sup> provided recommendations for management and or treatment of long COVID for older adult populations post-COVID. The New Zealand Ministry of Health<sup>(28)</sup> guideline recommended referral for specialist and or multidisciplinary assessment and support for older adults in the presence of mobility issues, communication issues, nutritional and swallowing issues, respiratory issues and fatigue.

The EuGMS<sup>(23)</sup> guideline provided recommendations for the rehabilitation of older adult populations post-COVID across a number of domains, such as somatic, functional, psychological, existential, and social. Recommended treatment goals and actions included management and optimisation of somatic geriatric syndromes (such as incontinence and insomnia), comorbidities, medication use, nutrition, and functional swallowing capacity. The EuGMS also recommended assisting older adults with their activities of daily living through self-management skills training, and compensation strategy skills for fatigue and cognitive impairment management. Additionally, timely diagnosis, treatment of psychological issues and provision of support to both patients and their family caregivers, (following the initial illness and at follow up by their primary care team) were also recommended.

Goal setting was recommended to improve social participation, and the use of shared decision-making was recommended for both patient and family caregivers in evaluation and treatment decisions. During the hospital discharge phase for older adults, the EuGMS recommended assessing COVID-19-related complications and their interaction with other comorbidities. This would be in addition to performing assessments across all symptom domains (that is, somatic, functional, psychological, existential, and social). Referral to relevant healthcare professionals for remediation was recommended where issues were identified. The EuGMS guideline also recommended the timely and detailed transfer of patient records to primary care professionals. COVID-19 patients discharged from hospital after ICU admission can be affected by a variety of problems, such as post-intensive care syndrome (PICS); this includes impairments in physical, cognitive and or mental functioning. The EuGMS advised that these patients require extra attention in relation to malnutrition, breathing issues, swallowing difficulties and oropharyngeal dysphagia. A focus on

the prevention of sputum retention, aspiration and pressure ulceration was also recommended.

A detailed overview of recommendations for management and or treatment of long COVID from all guidelines and or models of care included in this review is presented in Appendix 3 and Appendix 4. This includes recommendations for the management of additional symptoms such as anxiety and depression, orthostatic intolerance, dysphagia, voice impairment, headache, cough, and digestive symptoms.

### **3.5.3 Recommendations on service planning for long COVID**

Four guidelines<sup>(2, 13, 14, 16)</sup> and one model of care<sup>(41)</sup> (of the ten guidelines and one model of care deemed to be of higher quality) included recommendations concerning service planning and organisation for long COVID.

Recommendations on service planning and organisation specified the need for comprehensive multidisciplinary services for people with long COVID. Three guidelines<sup>(2, 13, 14)</sup> recommended the provision of integrated multidisciplinary services based on local needs and resources. These should include support staff and or core team members (for example, specialists in allied health, clinical psychology, nursing, rehabilitation medicine), all led by a physician with relevant skills and experience. To avoid fragmented care, the CAMFiC guideline<sup>(16)</sup> recommended the provision of additional staffing resources to support the care of those with long COVID. One guideline<sup>(2)</sup> and one model of care<sup>(41)</sup> recommended self-management and education resources for healthcare providers, through sharing of knowledge, skills and training across services. Two guidelines<sup>(13, 16)</sup> noted that primary care teams are well placed to coordinate multidisciplinary care.

Three guidelines<sup>(2, 13, 14)</sup> recommended shared decision-making and patient-centred care as core components in service planning for long COVID, with a hybrid approach of in-person and remote models, integrated across all healthcare settings.<sup>(14)</sup> The core functions recommended in service organisation for long COVID included: use of standardised assessment tools (such as the COVID-19 Yorkshire Rehabilitation Screen (C19-YRS)<sup>(46)</sup> and Alberta Health Services Post COVID-19 Functional Status Scale (PCFS)<sup>(47)</sup>) to systematically identify long COVID symptoms and to facilitate rehabilitation outcome measurement; a system to allow patient follow-up (such as a structured follow-up care plan); and an onward referral system (that is, referral to specialist care).<sup>(2, 14, 41)</sup> Four of the ten guidelines<sup>(2, 13, 14, 16)</sup> and the model of care<sup>(41)</sup> that were deemed to be of higher quality recommended continuity and coordination of care.

In addition, all four of the AAPMR guidelines, though not explicitly related to service planning, recommended continuity of care in terms of collaboration with specialists following onward referral.<sup>(22, 29, 31, 34)</sup> Three guidelines<sup>(2, 13, 14)</sup> and the model of

care<sup>(41)</sup> recommended agreement of local, integrated referral pathways between in-hospital, primary and community-based care, rehabilitation services, specialist services and specialist mental health services. Multidisciplinary team meetings were recommended to facilitate coordinated care with the use of multidisciplinary assessment clinics (where available).

### **Recommendations on service planning for long COVID in specific sub-groups**

Again, though not deemed to be higher quality guidelines, the AAP<sup>(39)</sup> guideline for paediatric populations recommended a team-based approach for children or adolescents with significant physical impairments or multimorbidities. This team-based approach should be coordinated by the primary care pediatrician, and include access to medical, surgical, occupational, and behavioural specialists, as needed.

Guidelines from the EuGMS<sup>(23)</sup> provided recommendations for service planning for older adult populations post-COVID. The EuGMS<sup>(23)</sup> recommended that the comprehensive geriatric assessment (CGA) be conducted by geriatrician or a geriatric rehabilitation specialist in conjunction with the wider multidisciplinary rehabilitation team, and that it should specify whether the rehabilitation should be provided in a geriatric rehabilitation facility, medical specialist rehabilitation facility or specialised pulmonary rehabilitation facility (if available). The choice should be tailored by matching the patients' needs to the medical, therapist and nursing provision available in the receiving facility. Based on the CGA, a decision for inpatient care, outpatient care or a combination of the two should be taken, depending on the available services, local circumstances and informal care available to the patient. The EuGMS guideline outlined the different care trajectories of older adults admitted to geriatric rehabilitation following an intensive care unit admission, a ward-based admission, or those admitted to rehabilitation from home. The EuGMS recommended a flexible and interdisciplinary approach to geriatric rehabilitation with collaboration across healthcare disciplines in instances where care facilities have fewer disciplines forming the multidisciplinary teams and also depending on the needs of the patient. Furthermore, the EuGMS recommended close collaboration between the geriatric rehabilitation team and a (clinical) pharmacist, given the impact of polypharmacy on rehabilitation and recovery and the changes to drug regimens which are typically a part of COVID-19 care.

For people with disabilities and their families, the New Zealand Ministry of Health<sup>(28)</sup> guideline recommended a holistic approach to service planning, including accessible peer support and also the provision of support to the caregivers of people with disabilities. Tailored supports for people with disabilities were also recommended as well as the involvement of experts in disability rehabilitation in long COVID management. It recommended that people with disabilities be prioritised for

assessment and treatment and that accessible communication, information, and treatment should be planned for, and available to, the individual.

A detailed overview of the recommendations for service planning for long COVID across all the guidelines and or models of care included in this review are presented in Appendix 3 and Appendix 4.

**Table 3.3 Matrix of recommendations for diagnosis and management and or treatment of long COVID**

| Included recommendations   | WHO <sup>(14)</sup> | NICE/RCGP/SIGN <sup>(2)</sup> | Australian C19 Taskforce <sup>(13)</sup> | CAMFiC <sup>(16)</sup> | ESCMID <sup>(21)</sup> | AAPMRd Cardiovascular <sup>(22)</sup> | AAPMRC Breathing Discomfort <sup>(29)</sup> | AAPMRa Cognitive Symptoms <sup>(34)</sup> | AAPMRb Fatigue <sup>(31)</sup> | Alberta Health Services <sup>(41)</sup> | Swiss <sup>(32)</sup> | ISP <sup>(35)</sup> | AAP <sup>(39)</sup> | EuGMS <sup>(23)</sup> |
|--|---------------------|-------------------------------|--|------------------------|------------------------|---------------------------------------|---|---|--------------------------------|---|-----------------------|---------------------|---------------------|-----------------------|
| <b>Diagnoses</b>   |                     |                               |  |                        |                        |                                       |   |   |                                |   |                       |                     |                     |                       |
| Assessment ≥4 weeks if experiencing new or persistent symptoms                     | ✓                   | ✓                             | ✓  | ✓                      | ✓                      | ✓                                     | ✓   | ✓   | ✓                              | ✓                                       |                       | ✓                   |                     |                       |
| Identify potential causes or conditions, after ruling out alternative diagnoses    |                     | ✓                             | ✓  | ✓                      | ✓                      | ✓                                     | ✓   | ✓   | ✓                              |   |                       |                     | ✓                   |                       |
| Screen hospitalised C19 patients on or after discharged                            |                     | ✓                             |  |                        |                        |                                       |   |   |                                | ✓                                       | ✓                     |                     |                     |                       |
| Shared decision-making   |                     | ✓                             | ✓  |                        |                        | ✓                                     |   |   |                                |   |                       |                     |                     | ✓                     |
| Support equity of access   |                     | ✓                             | ✓  |                        | ✓                      | ✓                                     | ✓   | ✓   | ✓                              |   |                       |                     |                     |                       |
| <b>General assessments and tests</b>   |                     |                               |  |                        |                        |                                       |   |   |                                |   |                       |                     |                     |                       |
| Assessment to include comprehensive patient clinical history and their medications |                     | ✓                             | ✓  | ✓                      | ✓                      | ✓                                     | ✓   | ✓   | ✓                              |   |                       |                     |                     |                       |
| Document details of the acute illness  |                     | ✓                             | ✓  |                        |                        |                                       |   |   |                                | ✓                                       |                       |                     |                     |                       |

| Included recommendations   | WHO <sup>(14)</sup> | NICE/RCGP/SIGN <sup>(2)</sup> | Australian C19 Taskforce <sup>(13)</sup> | CAMFiC <sup>(16)</sup> | ESCMID <sup>(21)</sup> | AAPMRd Cardiovascular <sup>(22)</sup> | AAPMRC Breathing Discomfort <sup>(29)</sup> | AAPMRa Cognitive Symptoms <sup>(34)</sup> | AAPMRb Fatigue <sup>(31)</sup> | Alberta Health Services <sup>(41)</sup> | Swiss <sup>(32)</sup> | ISP <sup>(35)</sup> | AAP <sup>(39)</sup> | EuGMS <sup>(23)</sup> |
|--|---------------------|-------------------------------|--|------------------------|------------------------|---------------------------------------|---|---|--------------------------------|---|-----------------------|---------------------|---------------------|-----------------------|
| Information on self-management provided at diagnosis                       |                     | ✓                             | ✓  |                        |                        |                                       |   |   |                                |   |                       |                     |                     |                       |
| Lab test decisions guided by symptomology                                  |                     | ✓                             | ✓  | ✓                      | ✓                      | ✓                                     |   | ✓   | ✓                              |   |                       |                     |                     |                       |
| 'Red flag' symptoms  |                     | ✓                             | ✓  | ✓                      |                        |                                       |   |   |                                |   |                       |                     | ✓                   |                       |
| Symptom-based assessment   |                     | ✓                             | ✓  | ✓                      | ✓                      | ✓                                     | ✓   | ✓   | ✓                              |   | ✓                     |                     |                     |                       |
| Use screening questionnaire  |                     | ✓                             | ✓  |                        |                        |                                       |   |   |                                | ✓                                       |                       |                     |                     |                       |
| <b>Symptom based assessments</b>   |                     |                               |  |                        |                        |                                       |   |   |                                |   |                       |                     |                     |                       |
| Assessments for fatigue  |                     |                               |  | ✓                      |                        |                                       |   |   | ✓                              |   |                       |                     |                     |                       |
| Assessments for persistent headache  |                     |                               |  | ✓                      |                        |                                       |   |   |                                |   |                       |                     |                     |                       |
| Assessments of cognitive dysfunction                                       |                     | ✓                             |  |                        |                        |                                       |   | ✓   |                                |   |                       |                     |                     |                       |
| Cardiac tests for cardiovascular symptoms                                  |                     |                               |  | ✓                      | ✓                      | ✓                                     |   |   |                                |   |                       |                     |                     |                       |
| Chest radiography for persistent respiratory symptoms                      |                     | ✓                             | ✓  | ✓                      | ✓                      | ✓                                     | ✓   |   |                                |   | ✓                     |                     | ✓                   |                       |
| Pulmonary function testing at 8 to 12 weeks persistent shortness of breath |                     |                               |  |                        | ✓                      |                                       | ✓   |   |                                |   | ✓                     |                     |                     |                       |



| Included recommendations  | WHO <sup>(14)</sup> | NICE/RCGP/SIGN <sup>(2)</sup> | Australian C19 Taskforce <sup>(13)</sup> | CAMFiC <sup>(16)</sup> | ESCMID <sup>(21)</sup> | AAPMRd Cardiovascular <sup>(22)</sup> | AAPMRC Breathing Discomfort <sup>(29)</sup> | AAPMRa Cognitive Symptoms <sup>(34)</sup> | AAPMRb Fatigue <sup>(31)</sup> | Alberta Health Services <sup>(41)</sup> | Swiss <sup>(32)</sup> | ISP <sup>(35)</sup> | AAP <sup>(39)</sup> | EuGMS <sup>(23)</sup> |
|---|---------------------|-------------------------------|--|------------------------|------------------------|---------------------------------------|---|---|--------------------------------|---|-----------------------|---------------------|---------------------|-----------------------|
| Tests for orthostatic intolerance or postural symptoms  |                     | ✓                             | ✓  |                        |                        |                                       |   |   |                                |   |                       |                     |                     |                       |
| <b>Treatment and or management</b>  |                     |                               |  |                        |                        |                                       |   |   |                                |   |                       |                     |                     |                       |
| <b>General</b>  |                     |                               |  |                        |                        |                                       |   |   |                                |   |                       |                     |                     |                       |
| Baseline measures and ongoing assessments shared across services                              | ✓                   | ✓                             | ✓  |                        |                        |                                       |   |   |                                | ✓                                       |                       |                     |                     |                       |
| Holistic, person-centred approach   |                     | ✓                             | ✓  |                        |                        |                                       |   |   |                                | ✓                                       |                       |                     |                     |                       |
| Information on self-management  | ✓                   | ✓                             |  | ✓                      |                        |                                       |   |   |                                | ✓                                       |                       |                     |                     |                       |
| Investigate symptoms that could affect the patient's ability before initiating rehabilitation | ✓                   | ✓                             |  |                        |                        |                                       | ✓   |   |                                |   |                       |                     |                     |                       |
| Multidisciplinary personalised approach to rehabilitation                                     |                     | ✓                             | ✓  | ✓                      |                        |                                       |   | ✓   | ✓                              | ✓                                       |                       |                     |                     |                       |
| <b>Specific</b>   |                     |                               |  |                        |                        |                                       |   |   |                                |   |                       |                     |                     |                       |
| Anosmia and or dysgeusia  | ✓                   |                               |  | ✓                      | ✓                      |                                       |   |   |                                |   |                       |                     | ✓                   |                       |
| Breathing discomfort  | ✓                   |                               |  |                        |                        |                                       | ✓   |   |                                |   | ✓                     |                     |                     |                       |
| Cardiac complications   |                     |                               |  |                        |                        | ✓                                     |   |   |                                |   |                       |                     |                     |                       |

| Included recommendations  | WHO <sup>(14)</sup> | NICE/RCGP/SIGN <sup>(2)</sup> | Australian C19 Taskforce <sup>(13)</sup> | CAMFiC <sup>(16)</sup> | ESCMID <sup>(21)</sup> | AAPMRd Cardiovascular <sup>(22)</sup> | AAPMRC Breathing Discomfort <sup>(29)</sup> | AAPMRa Cognitive Symptoms <sup>(34)</sup> | AAPMRb Fatigue <sup>(31)</sup> | Alberta Health Services <sup>(41)</sup> | Swiss <sup>(32)</sup> | ISP <sup>(35)</sup> | AAP <sup>(39)</sup> | EuGMS <sup>(23)</sup> |
|---|---------------------|-------------------------------|--|------------------------|------------------------|---------------------------------------|---|---|--------------------------------|---|-----------------------|---------------------|---------------------|-----------------------|
| Cognitive dysfunction   | ✓                   | ✓                             |  |                        |                        |                                       |   | ✓   |                                |   |                       |                     |                     |                       |
| Fatigue   | ✓                   |                               |  |                        |                        |                                       | ✓   |   |                                |   |                       |                     | ✓                   |                       |
| Headaches   |                     |                               |  |                        |                        |                                       |   |   |                                |   |                       |                     | ✓                   |                       |
| Neurodevelopmental symptom  |                     |                               |  |                        |                        |                                       |   |   |                                |   |                       |                     | ✓                   |                       |
| Pain  | ✓                   |                               |  | ✓                      |                        |                                       |   |   |                                |   |                       |                     |                     |                       |
| Post-exertional symptom exacerbation (PESE)   | ✓                   |                               | ✓  |                        |                        |                                       |   |   |                                |   |                       |                     | ✓                   |                       |
| <b>Service planning</b>   |                     |                               |  |                        |                        |                                       |   |   |                                |   |                       |                     |                     |                       |
| Agreed referral pathways between in-hospital care, primary and community-based care and specialist services | ✓                   | ✓                             | ✓  |                        |                        |                                       |   |   |                                | ✓                                       |                       |                     |                     |                       |
| Continuity and coordination of care   | ✓                   | ✓                             | ✓  | ✓                      |                        | ✓                                     | ✓   | ✓   | ✓                              | ✓                                       |                       |                     |                     |                       |
| Hybrid approach of in-person and remote models  | ✓                   | ✓                             | ✓  |                        |                        |                                       |   |   |                                |   |                       |                     |                     |                       |
| Integrated multidisciplinary services   | ✓                   | ✓                             | ✓  |                        |                        |                                       |   |   |                                |   |                       |                     |                     |                       |
| Primary care teams to coordinate multidisciplinary care   |                     |                               | ✓  | ✓                      |                        |                                       |   |   |                                |   |                       |                     |                     |                       |

| Included recommendations                        | WHO <sup>(14)</sup> | NICE/RCGP/SIGN <sup>(2)</sup> | Australian C19 Taskforce <sup>(13)</sup> | CAMFiC <sup>(16)</sup> | ESCMID <sup>(21)</sup> | AAPMRd Cardiovascular <sup>(22)</sup> | AAPMRC Breathing Discomfort <sup>(29)</sup> | AAPMRa Cognitive Symptoms <sup>(34)</sup> | AAPMRb Fatigue <sup>(31)</sup> | Alberta Health Services <sup>(41)</sup> | Swiss <sup>(32)</sup> | ISP <sup>(35)</sup> | AAP <sup>(39)</sup> | EuGMS <sup>(23)</sup> |
|---|---------------------|-------------------------------|--|------------------------|------------------------|---------------------------------------|---|---|--------------------------------|---|-----------------------|---------------------|---------------------|-----------------------|
| Resources and training for healthcare providers |                     | ✓                             |  |                        |                        |                                       |   |   |                                | ✓                                       |                       |                     |                     |                       |
| Team-based approach                             |                     |                               |  |                        |                        |                                       |   |   |                                |   |                       |                     | ✓                   |                       |

**Key:** AAP - American Academy of Pediatrics; AAPMR - American Academy of Physical Medicine and Rehabilitation; CAMFiC - Catalan Society of Family and Community Medicine; ESCMID - European Society of Clinical Microbiology and Infectious Diseases; EuGMS - European Geriatric Medicine Society; ISP - Italian Society of Pediatrics; NICE – National Institute for Health and Care Excellence; RCGP - Royal College of General Practitioners; SIGN - Scottish Intercollegiate Guidelines Network; Swiss - Swiss COVID Lung Study Group & the Swiss Society of Pulmonology; WHO – World Health Organization.

## 4 Discussion

Twenty-four guidelines<sup>(2, 13, 14, 16, 21-40)</sup> and two models of care,<sup>(41, 42)</sup> which provided recommendations on the diagnosis and management and or treatment of long COVID, were included in this review.

Overall, there was considerable variation in the definition of long COVID used across guidelines; these differences predominantly related to the time period following acute COVID-19, during which clinical symptoms could be attributed to long COVID. Four guidelines<sup>(2, 16, 23, 31)</sup> adopted the clinical case definition for long COVID developed by NICE,<sup>(2)</sup> and two guidelines<sup>(14, 38)</sup> adopted the WHO<sup>(48)</sup> definition. The remaining 18 guidelines and two models of care developed their own long COVID definition, of which ten guidelines<sup>(22, 26, 27, 29-32, 34, 37, 39)</sup> and two models of care<sup>(41, 42)</sup> defined long COVID as symptoms that persist for four or more weeks following acute COVID-19. Five guidelines<sup>(13, 21, 28, 35, 38)</sup> defined long COVID as symptoms that persist for 12 or more weeks. However, most guidelines and or models of care recognise three phases to infection and recovery. That is, the acute infection phase, post-acute phase (4 to 12 weeks) and long COVID (12 weeks and beyond). This aligns with the HSE's current interim model of care, which refers to post-acute COVID-19 as ongoing symptoms that persist from 4 to 12 weeks after acute infection, and to long COVID as symptoms beyond 12 weeks that are not attributable to an alternative diagnosis. The importance of a clinical evaluation and supportive care during the initial 4 to 12 weeks after acute COVID-19 was frequently emphasised across guidelines and or models of care. This is reflected in the HSE's current interim model of care with recognition of the urgent need to establish a national service for those that require specialist follow-up from 4 to 12 weeks following COVID-19, as well those with symptoms more than 12 weeks following COVID-19.

Recommendations from ten guidelines<sup>(2, 13, 14, 16, 21, 22, 29, 31, 32, 34)</sup> and one model of care<sup>(41)</sup> deemed to be of higher methodological quality (that is, achieved an overall assessment score of greater than 70% as per the AGREE GRS tool) were discussed in this report. Guidelines and or models of care that specifically addressed sub-groups, such as older people and paediatrics, were also discussed.

Nine guidelines<sup>(2, 13, 16, 21, 22, 29, 31, 32, 34)</sup> and one model of care<sup>(41)</sup> (deemed to be of higher quality) contained recommendations concerning the diagnosis of long COVID. There is currently no standard assessment protocol for long COVID, and consensus and conditional recommendations were common across the included guidelines.<sup>(49)</sup> Moreover, included guidelines were consistent in emphasising the broad and fluctuating range of symptoms associated with long COVID.<sup>(2, 14, 16, 21)</sup>

The included guidelines and or models of care consistently recommended the identification of the potential causes or conditions that may reasonably explain, be related to, or exacerbate the symptoms of long COVID.<sup>(2, 13, 16, 21, 22, 29, 31, 34)</sup> They report that the potential for a diagnosis of long COVID can be considered once alternative diagnoses have been ruled out. Guidelines consistently recommended holistic, person-centred assessments.<sup>(2, 13, 14)</sup> These holistic assessments should include a comprehensive assessment of the patient's history and examination of physical, cognitive, psychological and psychiatric symptoms, as well as functional abilities and consideration of the impact of the reported symptoms on their quality of life.<sup>(2, 13, 16, 21, 22, 29, 31, 34)</sup> These recommendations concerning holistic assessments are consistent with those outlined in the HSE's interim model of care.

Diagnosis of long COVID is further complicated in patients who are hospitalised or admitted to intensive care units with acute COVID-19, due to the overlap in presenting symptoms with post-intensive care syndrome (PICS).<sup>(21)</sup> PICS is a condition associated with new or worsening physical, cognitive or mental health complaints following critical illness.<sup>(50)</sup> The guideline from the Australian National COVID-19 Clinical Evidence Taskforce<sup>(13)</sup> recommended consideration of PICS in hospitalised patients due to the difficulty in distinguishing whether persisting symptoms are caused by COVID-19 or PICS.

The long COVID trajectory of those hospitalised following acute SARS-CoV-2 infection and those whose recovery took place in the community has been examined in the literature. One study reported consistent symptoms across hospitalised and non-hospitalised individuals, with the severity of a range of long COVID symptoms related to the underlying severity of the initial SARS-CoV-2 infection, regardless of hospitalisation status during acute COVID-19.<sup>(51)</sup> The authors inferred that reported symptoms were less likely to be a result of the hospital experience or PICS, but rather because of the unique underlying impact of long COVID on physiological processes.<sup>(51)</sup>

Our review highlights that there is currently no standard treatment or management protocol for long COVID. This issue has also been highlighted in the peer-reviewed literature.<sup>(49)</sup> In the absence of a strong evidence base, recommendations regarding care or management were again conditional or consensus-based. Treatment recommendations for certain long COVID symptoms, such as dyspnoea<sup>(13, 14, 21)</sup> and neurological manifestations,<sup>(33)</sup> involved the use of well-established clinical approaches based on existing guidelines.

Recommendations for referral to specialists with expertise in managing specific symptoms (for example, referral to a cardiologist for persistent cardiac complications<sup>(21)</sup> or referral to a pulmonologist for persistent respiratory issues<sup>(16, 28)</sup>) were consistent across guidelines and or models of care, as well as

recommendations for referral to an integrated multidisciplinary service. (2, 13, 14, 16, 19)  
Again, these recommendations are consistent with those outlined in the HSE's interim model of care.

Overall, there was consistency in recommendations for holistic, person-centred management of long COVID symptoms with an emphasis on shared decision-making.<sup>(2, 13, 14)</sup> This approach is consistent with that outlined in the HSE's interim model of care. Self-management strategies, lifestyle modification, education, and skills training were commonly recommended across guidelines and the model of care.<sup>(2, 13, 14, 16, 22, 23, 29, 31, 34, 41)</sup> There was a consistent acknowledgement of the impact post-exertional symptom exacerbation (PESE) may have on an individual's ability to participate in rehabilitation and thus the need to rule out PESE before prescribing any rehabilitation plan.<sup>(2, 14, 29)</sup>

Consistency was found across four of the higher-quality guidelines<sup>(2, 13, 14, 16)</sup> and one higher-quality model of care<sup>(41)</sup> that provided recommendations for service planning. The need for comprehensive multidisciplinary services for people with long COVID was highlighted across these recommendations. The recommended core and support staff for multidisciplinary services included, but was not limited to, occupational therapists, physiotherapists, speech and language therapists, clinical psychologists, nurses, and rehabilitation medicine specialists. One of the recommended core functions in a multidisciplinary service for long COVID included the use of standardised assessment tools to systematically identify long COVID symptoms and rehabilitation outcome measurement, with a focus on patient-reported outcome measures (for example, quality of life measures).

Continuity of care through structured follow-up care planning and coordination of care that included referral to specialist care where necessary, was also recognised as a core function, particularly in the WHO<sup>(14)</sup> guideline. Recommendations for establishing local, integrated referral pathways between in-hospital, primary and community-based care, rehabilitation services and specialist services, specialist mental health services, and multidisciplinary assessment clinics (where available) were also emphasised.<sup>(2, 13, 41)</sup> However, it was acknowledged that implementation of such recommendations can prove difficult due to staffing issues.<sup>(16)</sup>

The HSE's interim model of care proposes a three pillar approach to a national post-COVID service:

- 1) patient-led rehabilitation and recovery (with an online support and education platform to manage symptoms at home)
- 2) general assessment, support, and rehabilitation (supported by General Practice and primary care rehabilitation)
- 3) specialist assessment, support, and rehabilitation (by means of specialist acute hospital clinics supported by primary care health and social care)

professionals with early discharge back to primary care for ongoing follow up where appropriate).

In contrast to a number of international guidelines, the HSE's interim model of care does not explicitly emphasise the need for standardised assessment tools or structured patient follow-up.

Challenges to service planning include the myriad of symptoms associated with long COVID, with over 200 different symptoms cited in the literature.<sup>(3)</sup> Long COVID symptoms typically occur across multiple organ systems concurrently, with one system oftentimes dominating (for example, the cardiovascular system).<sup>(49)</sup> As pointed out by the majority of included guidelines and or models of care, long COVID symptoms can remain constant or individuals can experience fluctuating symptoms.<sup>(49)</sup> Estimating the prevalence of long COVID is also difficult due to variability in the definitions of long COVID across the scientific evidence, coupled with the limited methodological robustness of current epidemiological studies.<sup>(16)</sup> As such, it is challenging for health services to plan long COVID services.

Due to the novel nature of SARS-CoV-2 infection and long COVID, the evidence underpinning recommendations for diagnosis and management and or treatment of long COVID is still in its infancy, which is further reflected by the frequency with which new guidelines are being produced and or updated. Since our final search date (22 September 2022):

- the NICE<sup>(2)</sup> guideline was updated on the 3 November 2022
- the Australian National COVID-19 Clinical Evidence Taskforce<sup>(13)</sup> guideline was updated on the 7 December 2022
- the New Zealand Ministry of Health<sup>(28)</sup> guideline was updated on the 13 December 2022
- the CDC guidelines were changed from interim guidance to information for healthcare providers on 22 September 2022.<sup>(37)</sup>

Of note, the NICE<sup>(2)</sup> guideline included an additional recommendation to refer people with ongoing symptomatic COVID-19 or suspected post-COVID-19 syndrome urgently for psychiatric assessment if they have severe psychiatric symptoms or are displaying a high risk of self-harm or suicide. Similarly, the Australian National COVID-19 Clinical Evidence Taskforce<sup>(13)</sup> guideline was updated to include a conditional recommendation for the provision of psychosocial, psychological and psychiatric support, if indicated, for people with signs and symptoms of a new or exacerbated pre-existing mental health condition following acute COVID-19. No

additional recommendations for diagnosis and management and or treatment of long COVID were identified in the updated New Zealand Ministry of Health<sup>(28)</sup> guideline.

Three additional guidelines were also identified since 22 September 2022, namely AAPMR guidance for PASC in children and adolescents,<sup>(52)</sup> AAPMR guidance for autonomic dysfunction in PASC<sup>(53)</sup> and the Korean preliminary guidelines for the clinical evaluation and management of long COVID.<sup>(54)</sup> The AAPMR paediatric guidance<sup>(51)</sup> provided detailed guidance for assessment and treatment of common long COVID symptoms in children and adolescents across nine domains (that is, systemic and or constitutional, mental health and psychiatric, autonomic, neurological, respiratory and or pulmonary, cardiology, otolaryngology, musculoskeletal, and gastrointestinal). The AAPMR guidelines for autonomic dysfunction<sup>(50)</sup> provided a definition for autonomic dysfunction, that is, any disturbance of the autonomic nervous system, including autonomic symptoms and common autonomic disorders, such as postural orthostatic tachycardia syndrome (POTS), neurocardiogenic syncope, which is also known as vasovagal syncope, orthostatic hypotension and inappropriate sinus tachycardia. The guideline also provided comprehensive recommendations on diagnosis and treatment (pharmacological and nonpharmacological). In contrast, the HSE's interim model of care proposes an initial general approach to management of children and young people with long COVID. It proposes that age-appropriate arrangements should be put in place in a post-COVID Specialist Assessment Clinic, including support for psychological needs. Recommendations from the Korean<sup>(54)</sup> guidelines were largely consistent with those found across guidelines and or models of care included in the review. In addition the guideline included recommendations regarding immediate referral for patients with serious psychiatric symptoms or risk of self-harm or suicide to psychiatry.

The results of this review should be interpreted with consideration of a number of limitations. This review is a high level summary of the international, national and regional guidelines and or models of care for diagnosis and management and or treatment that were available in English. This review is not a living document and as such, only includes guidelines and or models of care available as of 22 September 2022. Any updates made to the included guidelines and or models of care following this date are not reflected in the results of this report. It is expected that guidelines and or models of care will be updated as new evidence emerges and as protocols for the diagnosis, management and treatment of long COVID become standardised.

## **5 Conclusions**

Twenty-four guidelines and two models of care were included in this review. The definition of long COVID differed across guidelines. Given the absence of a strong



evidence base, recommendations were typically conditional or consensus-based. Recommendations in the HSE's current interim model of care are broadly consistent with those outlined internationally. Recommendations on diagnosis consistently emphasised the broad and fluctuating range of symptoms associated with long COVID and the importance of clinical evaluation and supportive care during the initial 4 to 12 weeks after acute COVID-19. There was also a focus on the application of existing guidelines for specific symptoms. Recommendations consistently comprised a holistic, person-centred approach to both assessment and management and or treatment of long COVID, with an emphasis on shared decision-making to agree on the level of support and rehabilitation needed for the individual.

Across guidelines, the use of standardised tools was recommended when assessing patients for long COVID as well as the need for structured follow-up care plans. Self-management and skills training were consistently recommended for management of long COVID, supported by integrated, multidisciplinary personalised care, where appropriate. Monitoring and management of underlying medical conditions and lifestyle factors that could exacerbate symptoms were also frequently recommended. In terms of service planning, the included guidelines and or models of care highlighted the need for a focus on continuation and coordination of care for individuals with long COVID. This should be facilitated through a comprehensive, multidisciplinary service that includes core team members, such as physicians with relevant experience and specialists in allied health, clinical psychology, nursing, pharmacy and rehabilitation medicine.

It is expected that the approaches adopted to diagnosis and treatment of long COVID will change as the evidence base evolves.

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## Appendix 1 List of organisations searched

| Organisation name   | Organisation URL  |
|---|---|
| <b>Australia</b>  |   |
| Australian National Health and Medical Research Council             | <a href="https://www.nhmrc.gov.au/">https://www.nhmrc.gov.au/</a>   |
| Australian Government, Department of Health and Aged Care           | <a href="https://www.health.gov.au">https://www.health.gov.au</a>   |
| Royal Australian College of General Practitioners                   | <a href="https://racgp.org.au">https://racgp.org.au</a>   |
| <b>Austria</b>  |   |
| Austrian Society of General and Family Medicine                     | <a href="https://oegam.at">https://oegam.at</a>   |
| Federal Ministry of Education, Science and Research                 | <a href="https://www.bmbwf.gv.at">https://www.bmbwf.gv.at</a>   |
| <b>Belgium</b>  |   |
| Belgian Health Care Knowledge Centre                                | <a href="https://kce.fgov.be/en">https://kce.fgov.be/en</a>   |
| <b>Canada</b>   |   |
| Canadian Agency for Drugs and Technologies in Health                | <a href="https://www.cadth.ca/">https://www.cadth.ca/</a>   |
| Government of Canada  | <a href="https://www.canada.ca/en">https://www.canada.ca/en</a>   |
| McMaster GRADE centre   | <a href="https://cebgrade.mcmaster.ca/">https://cebgrade.mcmaster.ca/</a>   |
| Royal College of Physicians and Surgeons of Canada                  | <a href="https://www.royalcollege.ca/">https://www.royalcollege.ca/</a>   |
| <b>Denmark</b>  |   |
| Danish Health Authority   | <a href="https://www.sst.dk/en/English">https://www.sst.dk/en/English</a>   |
| <b>Estonia</b>  |   |
| Estonian Health Insurance Fund                                      | <a href="https://www.haigekassa.ee/en">https://www.haigekassa.ee/en</a>   |
| Ravijuhend  | <a href="https://www.ravijuhend.ee/">https://www.ravijuhend.ee/</a>   |
| <b>Finland</b>  |   |
| Finnish Institute for Health and Welfare                            | <a href="https://thl.fi/fi/">https://thl.fi/fi/</a>   |
| <b>France</b>   |   |
| Haute Autorite de Sante   | <a href="https://has-sante.fr/">https://has-sante.fr/</a>   |
| <b>Germany</b>  |   |
| Association of the Scientific Medical Societies                     | <a href="https://www.awmf.org/en/awmf.html">https://www.awmf.org/en/awmf.html</a>   |
| Federal Ministry of Health  | <a href="https://www.zusammengegenercorona.de/en/">https://www.zusammengegenercorona.de/en/</a>   |
| <b>Italy</b>  |   |
| Instituto Superiore di Sanita                                       | <a href="https://www.iss.it/">https://www.iss.it/</a>   |
| <b>Netherlands</b>  |   |
| Government of the Netherlands                                       | <a href="https://www.rijksoverheid.nl/">https://www.rijksoverheid.nl/</a>   |
| Ministry of Health, Welfare and Sport                               | <a href="https://www.government.nl/ministries/ministry-of-health-welfare-and-sport/">https://www.government.nl/ministries/ministry-of-health-welfare-and-sport/</a>               |
| <b>New Zealand</b>  |   |
| Ministry of Health  | <a href="https://www.health.govt.nz">https://www.health.govt.nz</a>   |
| New Zealand College of Public Health Medicine                       | <a href="https://nzcphm.org.nz/">https://nzcphm.org.nz/</a>   |
| The Best Practice Advocacy Centre New Zealand                       | <a href="https://bpac.org.nz/guidelines/">https://bpac.org.nz/guidelines/</a>   |
| <b>Norway</b>   |   |
| Norwegian Institute of Public Health                                | <a href="https://www.fhi.no">https://www.fhi.no</a>   |
| <b>Singapore</b>  |   |
| Ministry of Health  | <a href="https://www.moh.gov.sg">https://www.moh.gov.sg</a>   |
| <b>Spain</b>  |   |
| CAMFiC, Catalan Society of Family and Community Medicine, Catalonia | <a href="https://camfic.cat/">https://camfic.cat/</a>   |
| <b>Sweden</b>   |   |
| National Board of Health and Welfare                                | <a href="https://www.socialstyrelsen.se/en/regulations-and-guidelines/national-guidelines/">https://www.socialstyrelsen.se/en/regulations-and-guidelines/national-guidelines/</a> |
| Public Health Agency of Sweden                                      | <a href="https://www.folkhalsomyndigheten.se/the-public-health-agency-of-sweden/">https://www.folkhalsomyndigheten.se/the-public-health-agency-of-sweden/</a>                     |

| Organisation name  | Organisation URL  |
|--|---|
| <b>Switzerland</b>   |   |
| Federal Office of Public Health  | <a href="https://www.bag.admin.ch/bag/de/home.html">https://www.bag.admin.ch/bag/de/home.html</a> |
| Swiss Centre for International Health  | <a href="https://swisstph.ch/en/about/scih">https://swisstph.ch/en/about/scih</a>                 |
| <b>UK</b>  |   |
| Health Protection Scotland, Scotland   | <a href="https://www.hps.scot.nhs.uk/">https://www.hps.scot.nhs.uk/</a>                           |
| National Institute for Health and Care Excellence, UK                        | <a href="https://www.nice.org.uk/">https://www.nice.org.uk/</a>                                   |
| Scottish Intercollegiate Guidelines Network, Scotland                        | <a href="https://www.sign.ac.uk/">https://www.sign.ac.uk/</a>                                     |
| Public Health Agency of Northern Ireland, Northern Ireland                   | <a href="https://www.publichealth.hscni.net/">https://www.publichealth.hscni.net/</a>             |
| Royal College of General Practitioners, UK                                   | <a href="https://rcgp.org.uk/">https://rcgp.org.uk/</a>   |
| <b>US</b>  |   |
| Agency for Healthcare Research and Quality                                   | <a href="https://www.ahrq.gov/">https://www.ahrq.gov/</a>   |
| American College of Physicians   | <a href="https://www.acponline.org">https://www.acponline.org</a>                                 |
| Centers for Disease Control and Prevention                                   | <a href="https://www.cdc.gov/">https://www.cdc.gov/</a>   |
| National Academy of Medicine (previously known as the Institute of Medicine) | <a href="https://nam.edu/about-the-nam/">https://nam.edu/about-the-nam/</a>                       |
| <b>International</b>   |   |
| Australasian Faculty of Public Health Medicine                               | <a href="https://www.racp.edu.au/">https://www.racp.edu.au/</a>                                   |
| European Network for Health Technology Assessment                            | <a href="https://www.eunethta.eu/">https://www.eunethta.eu/</a>                                   |
| European Centre for Disease Prevention and Control                           | <a href="https://www.ecdc.europa.eu/en">https://www.ecdc.europa.eu/en</a>                         |
| Guidelines International Network   | <a href="https://g-i-n.net/">https://g-i-n.net/</a>   |
| World Health Organization  | <a href="https://www.who.int/">https://www.who.int/</a>   |



## Appendix 2 Grey literature searches

| Guideline sources          | Number of results | Date searched |
|----------------------------|-------------------|---------------|
| TRIP Database              | 20                | 22/09/2022    |
| BMJ Best Practice          | 4                 | 22/09/2022    |
| UptoDate                   | 16                | 22/09/2022    |
| International HTA Database | 7                 | 22/09/2022    |
| Epistimoikos               | 50                | 22/09/2022    |
| WHO COVID-19 Database      | 16                | 22/09/2022    |
| Google                     | 51                | 22/09/2022    |
| Google Scholar             | 37                | 22/09/2022    |
| COVID-END                  | 1                 | 22/09/2022    |
| Base                       | 2                 | 22/09/2022    |

## Appendix 3 Data extraction tables for clinical guidelines and or models of care relating to general long COVID

### Appendix 3.1 Data extraction table for Provincial Adult long COVID pathway

| Clinical guideline and or model of care characteristics  |  |
|--|--|
| <b>Endorsing organisation</b>  | Alberta Health Services  |
| <b>Title</b>   | Provincial Adult long COVID pathway  |
| <b>Country</b>   | Canada   |
| <b>Date published</b>  | September 2020   |
| <b>URL</b>   | <a href="https://www.albertahealthservices.ca/assets/info/ppih/if-ppih-covid-19-post-covid-rehab-taskforce-final-report.pdf">https://www.albertahealthservices.ca/assets/info/ppih/if-ppih-covid-19-post-covid-rehab-taskforce-final-report.pdf</a><br><a href="https://www.albertahealthservices.ca/assets/info/ppih/if-ppih-covid-19-provincial-adult-long-covid-pathway.pdf">https://www.albertahealthservices.ca/assets/info/ppih/if-ppih-covid-19-provincial-adult-long-covid-pathway.pdf</a><br><a href="https://www.albertahealthservices.ca/assets/info/ppih/if-ppih-covid-19-post-covid-rehab-response-framework-summary.pdf">https://www.albertahealthservices.ca/assets/info/ppih/if-ppih-covid-19-post-covid-rehab-response-framework-summary.pdf</a><br><a href="https://www.albertahealthservices.ca/assets/info/ppih/if-ppih-covid-19-post-covid-response-framework-summary-appendices.pdf">https://www.albertahealthservices.ca/assets/info/ppih/if-ppih-covid-19-post-covid-response-framework-summary-appendices.pdf</a> |
| <b>National or regional</b>  | Regional   |
| <b>Adapted from previous guidelines and or model of care? If so which guidelines and or model of care was it adapted from?</b> | N/A  |
| <b>Update(s) planned (including dates)</b>   | Current version was updated in March 2021. No indication for next update.  |
| Definition and diagnosis   |  |
| <b>Definition of long COVID used in the guideline and or model of care</b>   | <b>Post COVID-19 syndrome</b> <ul style="list-style-type: none"> <li>▪ Persons with COVID-19 who go on to experience debilitating symptoms 12 weeks after COVID-19 diagnosis, which may last for many months.</li> </ul>   |
| <b>Recommendations for diagnosis of long COVID</b>   | <b>The more frequent post COVID-19 symptoms reported across studies included:</b> <ul style="list-style-type: none"> <li>▪ Dyspnea</li> <li>▪ Fatigue</li> <li>▪ Cough</li> <li>▪ Headache</li> </ul>  |

|  |   |
|--|---|
|  | <ul style="list-style-type: none"> <li>▪ Anosmia</li> <li>▪ Cognitive impairment</li> <li>▪ Ageusia</li> <li>▪ Myalgia or joint pain</li> <li>▪ Less frequently noted was:             <ul style="list-style-type: none"> <li>○ Chronicity of sleep impairments</li> <li>○ Chest pain</li> <li>○ Tachycardia</li> <li>○ Gastrointestinal upset</li> <li>○ Muscle weakness</li> <li>○ Anxiety.</li> </ul> </li> </ul> <p><b>Post COVID-19 rehabilitation screening tools:</b></p> <ul style="list-style-type: none"> <li>▪ PCFS:             <ul style="list-style-type: none"> <li>○ <b>Grade 0-1 - Mild functional impairment:</b> Indicates an absence of any symptoms or negligible functional limitation as well as patients with persistent pain, depression or anxiety that does not limit activity.</li> <li>○ <b>Grade 2-3 – Moderate functional impairment:</b> Indicates a reduction in ability to perform certain activities or symptoms of pain or anxiety that reduce functional activities.</li> <li>○ <b>Grade 3-4 - Severe functional impairment:</b> Indicates an inability to perform certain activities and/or severe functional limitations that result in assistance to perform activities of daily living.</li> </ul> </li> <li>▪ Standardised screening of post COVID-19 symptoms using a checklist that was adopted from the UK National Health Service C19 YRS.</li> <li>▪ Scoring/evaluation to determine rehab needs.</li> </ul> <p><b>Post COVID-19 rehabilitation recommendations</b></p> <ul style="list-style-type: none"> <li>▪ Population 1 (hospitalised) patients with COVID-19 will be screened for potential rehabilitation needs at each transition of care using the (AHS-CRST), which is adapted from the C19-YRS.</li> <li>▪ Population 2 (community-only) patients with COVID-19 will be screened for potential rehabilitation needs using 4 key screening questions (to be finalised) that may be incorporated into existing screening and assessment tools in primary care, and continuing care (including home care and facility-based continuing care (long-term care and supportive living)).</li> </ul> |
| <b>Management and treatment</b>                                      |   |
| <b>Recommendations for treatment and or management of long COVID</b> | <ul style="list-style-type: none"> <li>▪ Comprehensive rehabilitation assessments of identified issues should be completed at every level of care where indicated by the rehabilitation screening. The assessments should include multi-system assessments that build on screening results.</li> </ul>  |

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|  | <ul style="list-style-type: none"> <li>▪ Many rehabilitation issues can, and should, be addressed by self-management, which must be supported across the care continuum.</li> <li>▪ Critical care: priority assessments are required for patients in ICU who (a) require extended mechanical ventilation, sedation and or prolonged bedrest; (b) are over 65 years of age; or (c) have chronic comorbidities.</li> <li>▪ Acute Care: screening results direct rehabilitation assessments in acute care. These assessments may target the following:             <ul style="list-style-type: none"> <li>○ cognition (e.g. Saint Louis University Mental Status Exam)</li> <li>○ physical function (e.g. 6-Minute Walk Test, Timed Up and Go Test)</li> <li>○ activities of daily living (e.g. dressing, feeding, toileting assessments)</li> <li>○ other outcomes (e.g. pulmonary function using spirometry, mental health using Hospital Anxiety and Depression Screen).</li> </ul> </li> </ul> <p><b>Inpatient rehabilitation</b></p> <ul style="list-style-type: none"> <li>▪ Where patients have multiple diagnoses including COVID-19, the diagnosis with the most impairments should determine the inpatient rehabilitation trajectory. Consultation with psychiatry may facilitate this process.</li> </ul> <p><b>Long-term care and supportive living</b></p> <ul style="list-style-type: none"> <li>▪ A principle-based approach has patients living in facility-based continuing care following similar recommendations as those living in the community, but providers will customise based on patient needs and goals of care, as well as resources.</li> </ul> <p><b>Community and outpatient rehabilitation</b></p> <ul style="list-style-type: none"> <li>▪ All patients should have access to educational resources on anticipated symptoms, exercises, and self-management (e.g. MyHealth.Alberta contains resources like the COVID19 discharge checklist).</li> <li>▪ Appropriate rehabilitation programming for patients will vary based on patient functioning and goals, as well as resource availability. Existing pathways will direct patients to community rehabilitation or home care based on eligibility and needs. Consideration of hybrid models of virtual and in-person care may be appropriate.</li> </ul> <p><b>Self-directed recovery (particularly for patients never hospitalised for COVID-19)</b></p> <ul style="list-style-type: none"> <li>▪ Primary care providers are the lead care providers of, and can share resources with, patients who are directing their own recovery. Existing educational resources can support patients, such as Health Link®/RAL and MyHealth.Alberta.</li> </ul> <p><b>Discharge and or transition planning</b></p> |
|--|--|

|  |   |
|--|---|
|  | <ul style="list-style-type: none"> <li>▪ A process to track and support patients with rehabilitation needs post-COVID19 should align with the Medical Officer of Health direction, and should ensure rehabilitation considerations in discharge documents, data monitoring, patient/family involvement, appropriate triage processes, education, evaluation strategies and communication strategies.</li> <li>▪ A central intake or transition and discharge coordinator should be embedded within existing services (including Health Link®/RAL or institutions) to identify rehabilitation needs in the community and support patients in wayfinding and transition.</li> <li>▪ Patient education resource and support packages should be compiled, particularly for Population 1 (hospitalised), at transition to community. This should include basic exercises, recommendations for recovery, strategies for well-being and mental health, referrals to appropriate community rehabilitation, as well as additional interventions (e.g. resources on smoking cessation, addictions, and vaccination).</li> <li>▪ AHS Communications should be engaged to raise public awareness and to develop and implement the communication strategies.</li> </ul> <p><b>Longitudinal follow-up</b></p> <ul style="list-style-type: none"> <li>▪ A repeated-measures, longitudinal follow-up of all patients with COVID-19 at 3, 6 and 12 months post hospital-discharge (Population 1) or post-diagnosis (Population 2) is recommended for further rehabilitation assessment and management.</li> <li>▪ Two needs-assessment tools are recommended:             <ul style="list-style-type: none"> <li>○ EQ-5D-5L (a validated, AHS-approved, general quality of life tool).</li> <li>○ The proposed AHS-PLMT, which is also based on the C19-YRS.</li> </ul> </li> <li>▪ Virtual telehealth services (e.g. Health Link®/RAL) will follow-up directly with patients to identify unmet rehabilitation needs under the longitudinal follow-up approach.             <ul style="list-style-type: none"> <li>○ The telehealth clinicians will assess patients recovering from COVID-19.</li> <li>○ Where the AHS-PLMT triggers further rehabilitation assessment, the clinicians will use the Primary Care Referral Letters to engage primary care clinicians to follow-up and determine appropriate clinical rehabilitation steps.</li> </ul> </li> <li>▪ The Physicians’ Learning Program will undertake the analysis of longitudinal data for quality improvement and program planning purposes.</li> </ul> |
| <b>Service planning</b>                                    |   |
| <b>Recommendations for service planning for long COVID</b> | <p>PCRF includes 3 care pathways across the care continuum, specifically targeting in-hospital care, continuing care, and community-based care, with 3 key elements:</p> <ol style="list-style-type: none"> <li>(1) The use of specific symptom screening and assessment tools to systematically identify PCC symptoms and functional impairments.</li> <li>(2) Pathways to determine patients’ rehabilitation trajectory and to guide their transition between care settings.</li> <li>(3) Self-management and education resources for patients and providers.</li> </ol>  |

**Key:** AHS - Alberta health services; AHS-CRST – Alberta health services-COVID19 rehabilitation screening tool; AHS-PLMT – Alberta health services-post COVID-19 long-term monitoring tool; C19 YRS - COVID-19 Yorkshire rehabilitation screening tool; ICU – intensive care unit; N/A – not applicable; PCC – post COVID condition; PCFS - post COVID-19 functional status scale; PCRF - provincial post COVID-19 rehabilitation response framework.

**Appendix 3.2 Data extraction table for COVID-19 rapid guideline: managing the long-term effects of COVID-19**

| <b>Clinical guideline and or model of care characteristics</b>   |   |
|--|---|
| <b>Endorsing Organisation</b>  | The National Institute for Health and Care Excellence (NICE), the Scottish Intercollegiate Guidelines Network (SIGN) and the Royal College of General Practitioners (RCGP)  |
| <b>Title</b>   | COVID-19 rapid guideline: managing the long-term effects of COVID-19  |
| <b>Country</b>   | UK  |
| <b>Date Published</b>  | 18 December 2020  |
| <b>URL</b>   | <a href="https://app.magicapp.org/#/guideline/EQpzKn/section/EeyPzE">https://app.magicapp.org/#/guideline/EQpzKn/section/EeyPzE</a>   |
| <b>National or regional</b>  | National  |
| <b>Adapted from previous guidelines and or model of care? If so which guidelines and or model of care was it adapted from?</b> | N/A   |
| <b>Update(s) planned (including dates)</b>   | Version 1.17 19 May 2022; Living guideline, will be continuously reviewed and updated in response to emerging evidence.   |
| <b>Definition and diagnosis</b>  |   |
| <b>Definition of long COVID used in the guideline and or model of care</b>   | <p><b>Ongoing symptomatic COVID-19</b></p> <ul style="list-style-type: none"> <li>Signs and symptoms of COVID-19 from 4 weeks up to 12 weeks.</li> </ul> <p><b>Post-COVID-19 syndrome</b></p> <ul style="list-style-type: none"> <li>Signs and symptoms that develop during or after an infection consistent with COVID-19, continue for more than 12 weeks and are not explained by an alternative diagnosis. It usually presents with clusters of symptoms, often overlapping, which can fluctuate and change over time and can affect any system in the body. Post-COVID-19 syndrome may be considered before 12 weeks while the possibility of an alternative underlying disease is also being assessed.</li> </ul> <p><b>Long COVID</b></p> <ul style="list-style-type: none"> <li>In addition to the clinical case definitions, the term 'long COVID' is commonly used to describe signs and symptoms that continue or develop after acute COVID-19. It includes both ongoing symptomatic COVID-19 (from 4 to 12 weeks) and post-COVID-19 syndrome (12 weeks or more).</li> </ul> |
| <b>Recommendations for diagnosis of long COVID</b>   | <p><b>Symptoms</b></p> <p>Symptoms after acute COVID-19 are highly variable and wide ranging. The most commonly reported symptoms include (but are not limited to) the following:</p>   |

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|  | <ul style="list-style-type: none"><li>▪ respiratory symptoms:<ul style="list-style-type: none"><li>○ breathlessness</li><li>○ cough</li></ul></li><li>▪ cardiovascular symptoms:<ul style="list-style-type: none"><li>○ chest tightness</li><li>○ chest pain</li><li>○ palpitations</li></ul></li><li>▪ generalised symptoms:<ul style="list-style-type: none"><li>○ fatigue</li><li>○ fever</li><li>○ pain</li></ul></li><li>▪ neurological symptoms:<ul style="list-style-type: none"><li>○ cognitive impairment ('brain fog', loss of concentration or memory issues)</li><li>○ headache</li><li>○ sleep disturbance</li><li>○ peripheral neuropathy symptoms (pins and needles and numbness)</li><li>○ dizziness</li><li>○ delirium (in older populations)</li><li>○ mobility impairment</li><li>○ visual disturbance</li></ul></li><li>▪ gastrointestinal symptoms:<ul style="list-style-type: none"><li>○ abdominal pain</li><li>○ nausea and vomiting</li><li>○ diarrhoea</li><li>○ weight loss and reduced appetite</li></ul></li><li>▪ musculoskeletal symptoms:<ul style="list-style-type: none"><li>○ joint pain</li><li>○ muscle pain</li></ul></li><li>▪ ear, nose and throat symptoms:<ul style="list-style-type: none"><li>○ tinnitus</li><li>○ earache</li><li>○ sore throat</li><li>○ dizziness</li><li>○ loss of taste and/or smell</li><li>○ nasal congestion</li></ul></li><li>▪ dermatological symptoms:</li></ul> |
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|  | <ul style="list-style-type: none"> <li>○ skin rashes</li> <li>○ hair loss</li> <li>▪ psychological/psychiatric symptoms: <ul style="list-style-type: none"> <li>○ symptoms of depression</li> <li>○ symptoms of anxiety</li> <li>○ symptoms of post-traumatic stress disorder</li> </ul> </li> </ul> <p>The following symptoms and signs are less commonly reported in children and young people than in adults:</p> <ul style="list-style-type: none"> <li>▪ shortness of breath</li> <li>▪ persistent cough</li> <li>▪ pain on breathing</li> <li>▪ palpitations</li> <li>▪ variations in heart rate</li> <li>▪ chest pain</li> </ul> <p><b>Identification – recommendation</b></p> <ul style="list-style-type: none"> <li>▪ For people with new or ongoing symptoms after acute COVID-19, suspect (evidence based): <ul style="list-style-type: none"> <li>○ ongoing symptomatic COVID-19 if people present with symptoms 4 to 12 weeks after the start of acute COVID-19 or</li> <li>○ post-COVID-19 syndrome if the person’s symptoms have not resolved 12 weeks after the start of acute COVID-19.</li> </ul> </li> <li>▪ For people who are experiencing new or ongoing symptoms 4 weeks or more after acute COVID-19, offer an initial consultation and use shared decision-making to discuss and agree with the person whether it should be remote or in person (based on expert testimony).</li> <li>▪ Based on the initial consultation, use shared decision-making to discuss and agree with the person whether they need a further assessment and whether this should be remote or in person. Take into account whether they may have symptoms that need investigating in person or require urgent referral to an appropriate service (based on expert testimony paired with consistent panel expertise).</li> <li>▪ A healthcare professional in secondary care should offer a follow-up consultation at 6 weeks after discharge to people who have been in hospital with acute COVID-19 to check for new or ongoing symptoms or complications (based on patient experience and panel expertise).</li> </ul> <p><b>Identification - consensus recommendations</b></p> <ul style="list-style-type: none"> <li>▪ Provide all information in accessible and age-appropriate formats so that people can understand and take part in decisions about their care. Follow relevant national guidance on communication, providing information (including different formats and languages) and shared decision-making.</li> </ul> |
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|  | <ul style="list-style-type: none"> <li>▪ Support access to assessment and care for people with new or ongoing symptoms after acute COVID-19, particularly for those in underserved or vulnerable groups who may have difficulty accessing services, e.g., by: <ul style="list-style-type: none"> <li>○ Providing extra time or additional support (such as an interpreter or advocate) during consultations.</li> <li>○ Raising awareness about possible new or ongoing symptomatic COVID-19 or post-COVID-19 syndrome – this may include working with local community leaders or organisations – particularly in vulnerable groups and black, Asian and minority ethnic groups.</li> </ul> </li> </ul> <p><b>Identification - conditional recommendations</b></p> <ul style="list-style-type: none"> <li>▪ Consider using a screening questionnaire as part of the initial consultation to help capture all of the person’s symptoms. These should only be used in conjunction with clinical assessment.</li> <li>▪ Consider follow up by primary care or community services for people in vulnerable or high-risk groups who have self-managed in the community after suspected or confirmed acute COVID-19.</li> </ul> <p><b>Assessment - recommendation (evidence based)</b></p> <ul style="list-style-type: none"> <li>▪ For people with ongoing symptomatic COVID-19 or suspected post-COVID-19 syndrome who have been identified as needing an assessment, use a holistic, person-centred approach. Include a comprehensive clinical history and appropriate examination that involves assessing physical, cognitive, psychological and psychiatric symptoms, as well as functional abilities. Include the below in the comprehensive clinical history: <ul style="list-style-type: none"> <li>○ history of acute COVID-19 (suspected or confirmed)</li> <li>○ the nature and severity of previous and current symptoms</li> <li>○ timing and duration of symptoms since the start of acute COVID-19</li> <li>○ history of other health conditions</li> <li>○ exacerbation of pre-existing conditions</li> </ul> </li> <li>▪ Be aware that people can have wide-ranging and fluctuating symptoms after acute COVID-19, which can change in nature over time.</li> <li>▪ Discuss the person’s experience of their symptoms and how their life and activities have been affected, including work, education, mobility and independence. Ask about any feelings of worry or distress. Listen to their concerns with empathy and acknowledge the impact on their day-to-day life.</li> </ul> <p><b>Assessment – recommendations (based on expert testimony paired with consistent panel expertise)</b></p> <ul style="list-style-type: none"> <li>▪ For people who may benefit from support during their assessment, e.g., to help describe their symptoms, include a family member or caregiver in discussions if the person agrees.</li> <li>▪ If the person reports new cognitive symptoms, use a validated screening tool to measure any impairment and impact.</li> </ul> |
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|  | <p><b>Investigations and referral – recommendation (based on patient experience paired with consistent panel expertise)</b></p> <ul style="list-style-type: none"> <li>▪ Offer tests and investigations tailored to people’s signs and symptoms to rule out acute or life threatening complications and find out if symptoms are likely to be caused by ongoing symptomatic COVID-19, post COVID-19 syndrome or could be a new, unrelated diagnosis.</li> <li>▪ Refer people with ongoing symptomatic COVID-19 or suspected post-COVID-19 syndrome urgently to the relevant acute services if they have signs or symptoms that could be caused by an acute or life-threatening complication, including (but not limited to): <ul style="list-style-type: none"> <li>○ hypoxaemia or oxygen desaturation on exercise</li> <li>○ signs of severe lung disease</li> <li>○ cardiac chest pain</li> <li>○ paediatric inflammatory multisystem syndrome – temporally associated with SARS-CoV-2 (PIMS-TS)</li> </ul> </li> <li>▪ Refer people with ongoing symptomatic COVID-19 or suspected post-COVID-19 syndrome urgently for psychiatric assessment if they have severe psychiatric symptoms or are displaying high risk of self-harm or suicide.</li> </ul> <p><b>Investigations and referral – consensus recommendations</b></p> <ul style="list-style-type: none"> <li>▪ For people with postural symptoms, e.g., palpitations or dizziness on standing, carry out lying and standing blood pressure and heart rate recordings (3-minute active stand test for orthostatic hypotension, or 10 minutes if you suspect postural tachycardia syndrome, or other forms of orthostatic intolerance).</li> </ul> <p><b>Investigations and referral - conditional recommendations</b></p> <ul style="list-style-type: none"> <li>▪ Decisions about blood tests should be guided by the person's symptoms. If clinically indicated, offer blood tests, which may include a full blood count, kidney and liver function tests, C-reactive protein, ferritin, BNP, HbA1c and thyroid function tests.</li> <li>▪ Consider supported self-monitoring at home, if this is agreed through shared decision-making as part of the person’s assessment. This may include heart rate, blood pressure, pulse oximetry or symptom diaries. Ensure that people have clear instructions on how to use any equipment and parameters for when to seek further help.</li> <li>▪ If appropriate, offer an exercise tolerance test suited to the person’s ability (e.g., the 1-minute sit-to-stand test). During the exercise test, record level of breathlessness, heart rate and oxygen saturation. Follow an appropriate protocol to carry out the test safely.</li> <li>▪ Offer a chest X-ray by 12 weeks after acute COVID-19 only if the person has continuing respiratory symptoms and it is clinically indicated. Chest X-ray appearances alone should not determine the need for referral for further care.</li> </ul> |
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|   | <ul style="list-style-type: none"> <li>▪ Follow relevant national or local guidelines on referral for people who have anxiety and mood disorders or other psychiatric symptoms. Consider referral for psychological therapies if they have common mental health symptoms, such as symptoms of mild anxiety and mild depression or refer to a liaison psychiatry service if they have more complex needs (especially if they have a complex physical and mental health presentation)</li> <li>▪ After ruling out acute or life-threatening complications and alternative diagnoses, consider referring people to an appropriate service, such as an integrated multidisciplinary assessment service, any time from 4 weeks after the start of acute COVID-19.</li> </ul>  |
| <b>Management and treatment</b>   |  |
| <p><b>Recommendations for treatment and or management of long COVID</b></p> | <p><b>Planning care – recommendation (based on patient experience paired with consistent panel expertise)</b></p> <ul style="list-style-type: none"> <li>▪ After the holistic assessment, discuss with the person (and their family or caregivers, if appropriate) the options available and what each involves. These should include:             <ul style="list-style-type: none"> <li>○ Advice on self-management, with the option of supported self-management and one or more of the following, depending on clinical need and local pathways:                 <ul style="list-style-type: none"> <li>▪ support from integrated and coordinated primary care, community, rehabilitation and mental health services</li> <li>▪ referral to an integrated multidisciplinary assessment service</li> <li>▪ referral to a specialist care for specific complications.</li> </ul> </li> </ul> </li> <li>▪ Use shared decision-making to agree what support and rehabilitation the person needs, including how and when it should be provided. When discussing with the person the appropriate level of support and management:             <ul style="list-style-type: none"> <li>○ Take account of the overall impact their symptoms are having on their life and usual activities, even if each individual symptom alone may not warrant referral.</li> <li>○ Look at the overall trajectory of their symptoms, taking into account that symptoms often fluctuate and recur so they might need different levels of support at different times.</li> </ul> </li> </ul> <p><b>Management – Recommendation (based on patient experience and expert testimony paired with consistent panel expertise)</b></p> <ul style="list-style-type: none"> <li>▪ Give advice and information on self-management to people with ongoing symptomatic COVID-19 or post-COVID-19 syndrome, starting from their holistic assessment. This should include:             <ul style="list-style-type: none"> <li>○ Ways to self-manage their symptoms, such as setting realistic goals.</li> <li>○ Who to contact if they are worried about their symptoms or they need support with self-management.</li> <li>○ Sources of advice and support, including support groups, social prescribing, online forums and apps.</li> <li>○ How to get support from other services, including social care, housing and employment, and advice about financial support.</li> </ul> </li> </ul> |

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|  | <ul style="list-style-type: none"> <li>○ Information about new or continuing symptoms of COVID-19 that the person can share with their family, caregivers and friends.</li> <li>■ Support people in discussions with their school, college or employer about returning to education or work, e.g. by having a phased return.</li> <li>■ Use a multidisciplinary approach to guide rehabilitation, including physical, psychological and psychiatric aspects of management. Ensure that any symptoms that could affect the person being able to start rehabilitation safely have been investigated first.</li> <li>■ Work with the person (and their family or caregivers, if appropriate) to develop a personalised rehabilitation and management plan that is recorded in a rehabilitation prescription and should include: <ul style="list-style-type: none"> <li>○ Areas of rehabilitation and interventions based on their assessment.</li> <li>○ Helping the person to decide and work towards goals.</li> <li>○ How to manage and monitor their symptoms, taking into account that these may fluctuate, and what to do if symptoms return or change.</li> </ul> </li> </ul> <p><b>Management - Consensus Recommendations</b></p> <ul style="list-style-type: none"> <li>■ Consider additional support for people with ongoing symptomatic COVID-19 or post-COVID-19 syndrome who may be vulnerable, e.g., older people and people with complex needs. Additional support may include short-term care packages, advance care planning and support with social isolation, loneliness and bereavement, if relevant.</li> </ul> <p><b>Management - Conditional Recommendations</b></p> <ul style="list-style-type: none"> <li>■ Encourage people to keep a record of, or use a tracking app to monitor, their goals, recovery and any changes in their symptoms.</li> <li>■ Consider referral from 4 weeks for specialist advice for children with ongoing symptomatic COVID-19 or post-COVID-19 syndrome.</li> </ul> <p><b>Follow up, monitoring and discharge – Recommendation (based on patient experience paired with consistent panel expertise)</b></p> <ul style="list-style-type: none"> <li>■ Use shared decision-making to decide how often follow up and monitoring are needed, which healthcare professionals should be involved and whether appointments should be carried out in person or remotely. Take into account: <ul style="list-style-type: none"> <li>○ The person's needs and the services involved.</li> <li>○ The person's symptoms, including new or worsening symptoms, and the effects of these on the person's life and wellbeing.</li> <li>○ Availability, clinical suitability and the person's preferences for in-person or remote appointments.</li> </ul> </li> </ul> |
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|   | <ul style="list-style-type: none"> <li>▪ Use shared decision-making to discuss and agree plans for discharge from rehabilitation and care, taking into account the person’s preferences, goals and social support.</li> </ul> <p><b>Follow up, monitoring and discharge – Consensus recommendation</b></p> <ul style="list-style-type: none"> <li>▪ Be alert to symptoms developing that could mean referral or investigation is needed, following recommendations in the section on assessment.</li> </ul> <p><b>Sharing information and continuity of care – Recommendation (based on patient experience paired with consistent panel expertise)</b></p> <ul style="list-style-type: none"> <li>▪ Ensure effective information sharing and integrated working by sharing clinical records and care and rehabilitation plans promptly between services and through multidisciplinary meetings, either virtual or in person.</li> <li>▪ Provide continuity of care with the same healthcare professional or team as much as possible, e.g., by providing a care coordinator or a single point of contact.</li> </ul> <p><b>Sharing information and continuity of care – Consensus recommendation</b></p> <ul style="list-style-type: none"> <li>▪ Give people a copy of their care plans or records to keep, including their discharge letters, clinical records and rehabilitation plans and prescriptions.</li> <li>▪ Include baseline measures as well as ongoing assessments in information shared between services, including when the person is discharged from hospital. E.g., resting oxygen saturation and heart rate, and the results of functional assessment.</li> </ul> |
| <b>Service planning</b>   |  |
| <p><b>Recommendations for service planning for long COVID</b></p> | <p><b>Service organisation – Recommendation (based on patient experience and expert testimony paired with consistent panel expertise)</b></p> <ul style="list-style-type: none"> <li>▪ Provide access to multidisciplinary services, if available, (these could be ‘one-stop’ clinics) for assessing physical and mental health symptoms and carrying out further tests and investigations. Services should be led by a doctor with relevant skills and experience and appropriate specialist support, taking into account the variety of presenting symptoms.</li> <li>▪ Provide integrated, multidisciplinary rehabilitation services, based on local need and resources. Healthcare professionals should have a range of specialist skills, with expertise in managing fatigue and respiratory symptoms (including breathlessness). Additional expertise may be needed depending on the age and symptoms of the person. The core team could include, but not be limited to, the following specialist areas:             <ul style="list-style-type: none"> <li>○ Occupational therapy</li> <li>○ Physiotherapy</li> <li>○ Clinical psychology and psychiatry</li> <li>○ Rehabilitation medicine</li> </ul> </li> </ul>  |

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|  | <ul style="list-style-type: none"><li>○ Other areas of expertise could also include, but are not limited to, rheumatology, neurology rehabilitation, cardiology, paediatrics, dietetics, speech and language therapy, nursing, pharmacy, social care and support to return to education or work or usual activities.</li><li>■ Agree local, integrated referral pathways between primary and community care, rehabilitation services and specialist services, multidisciplinary assessment clinics (where available) and specialist mental health services.</li></ul> <p><b>Service organisation – Consensus Recommendations</b></p> <ul style="list-style-type: none"><li>■ Share knowledge, skills and training between services to help practitioners in the community provide assessments and interventions, such as 1-minute sit-to-stand tests and breathlessness training.</li></ul> |
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**Key:** BNP - B-type natriuretic peptide.

**Appendix 3.3 Data extraction table for Interim COVID-19 Clinical Management Guidelines**

| <b>Clinical guideline and or model of care characteristics</b>   |  |
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| <b>Endorsing Organisation</b>  | COVID-19 Clinical Management Committee (CCMC)  |
| <b>Title</b>   | Interim COVID-19 Clinical Management Guidelines  |
| <b>Country</b>   | Singapore  |
| <b>Date Published</b>  | 15 April 2021  |
| <b>URL</b>   | <a href="https://www.moh.gov.sg/docs/librariesprovider4/default-document-library/interim-covid-19-clinical-management-guidelines-(summary-document).pdf">https://www.moh.gov.sg/docs/librariesprovider4/default-document-library/interim-covid-19-clinical-management-guidelines-(summary-document).pdf</a>  |
| <b>National or regional</b>  | National   |
| <b>Adapted from previous guidelines and or model of care?<br/>If so which guidelines and or model of care was it adapted from?</b> | N/A  |
| <b>Update(s) planned (including dates)</b>   | N/R  |
| <b>Definition and diagnosis</b>  |  |
| <b>Definition of long COVID used in the guideline and or model of care</b>   | <p><b>Long-haul Covid-19</b></p> <ul style="list-style-type: none"> <li>▪ Persistent post-acute COVID-19 symptoms have been reported, with some coining it as “long-haul COVID-19”. Chronic symptoms have been reported to persist beyond what is generally expected of an acute viral infection, which may entail fatigue, cough, shortness of breath, headache/body ache, diarrhoea, nausea, chest/abdominal pain and confusion.</li> </ul>  |
| <b>Recommendations for diagnosis of long COVID</b>   | <p><b>Psychological and Mental Health in COVID-19 patients</b></p> <ul style="list-style-type: none"> <li>▪ We recommend considering comprehensive psycho-social care assessment and support to at risk and vulnerable patients inflicted with COVID-19 infection and/or persistent post-acute COVID-19 infection symptoms, including but not limited to elderly, and individuals living alone who may experience barriers to care. (Level of evidence V, Grade of evidence D, Strength of recommendation Moderate)</li> <li>▪ For COVID-19 recovered patients with persistent post-acute COVID-19 neuropsychiatric symptoms, we recommend Psychiatric Consultation Liaison multidisciplinary team (Psych CL-MDT) assessment and management of persisting neuropsychiatric presentations and persistent post-acute COVID-19 symptoms arising from COVID-19 infection. (Level of evidence IV, Grade of evidence C, Strength of recommendation Moderate)</li> <li>▪ Persistent post-acute COVID-19 symptoms: <ul style="list-style-type: none"> <li>○ insomnia, circadian rhythm change</li> </ul> </li> </ul> |



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|   | <ul style="list-style-type: none"> <li>○ cognitive impairment</li> <li>○ chronic fatigue syndrome</li> <li>○ adjustment disorder</li> <li>○ major depressive disorder</li> <li>○ post-traumatic stress disorder</li> <li>○ panic disorder</li> <li>○ obsessive compulsive disorder</li> <li>○ psychotic disorder</li> <li>○ suicidal ideation</li> <li>○ lifestyle changes (weight gain, increased alcohol and tobacco use)</li> <li>○ exacerbation of dysfunction arising from pre-morbid personality disorder</li> </ul> <ul style="list-style-type: none"> <li>■ Chronic symptoms have been reported in recovered COVID-19 patients, and include fatigue, cough, shortness of breath, headache/body ache, diarrhea, nausea, chest/abdominal pain and confusion. These symptoms may be due to organ injury from COVID-19 infection, post viral chronic fatigue syndrome, neurological dysfunction or psychological syndromes. We recommend opportunistic screening of these symptoms in recovered patients. (Level of evidence V, Grade of evidence D, Strength of recommendation Weak)</li> <li>■ This entity remains undefined in our population. We recommend further research into the surveillance for prevalence and severity of lingering COVID symptoms in our recovered patients. (Level of evidence V, Grade of evidence D, Strength of recommendation Weak)</li> </ul> |
| <b>Management and treatment</b>   |   |
| <p><b>Recommendations for treatment and or management of long COVID</b></p> | <p><b>Screening guidance and suggestion for referral</b></p> <ul style="list-style-type: none"> <li>■ Exertional dyspnea, chest pain, chronic cough             <ul style="list-style-type: none"> <li>○ Exertional dyspnoea should be graded by the New York Heart Association classification. A cardiovascular and respiratory examination should be performed, and a CXR and/or an ECG may be done as appropriate. Consider referral to Cardiology or Respiratory Medicine as appropriate.</li> </ul> </li> <li>■ Cognitive impairment             <ul style="list-style-type: none"> <li>○ Consider referral to Neurology or Psychiatry after excluding organic cause.</li> </ul> </li> <li>■ Mood disorders - Anxiety/depression             <ul style="list-style-type: none"> <li>○ Assess suicide risks. Perform medical evaluation. Consider referral to Psychiatry based on severity as appropriate.</li> </ul> </li> <li>■ Fatigue             <ul style="list-style-type: none"> <li>○ Patient should be evaluated for medical causes as well as psychosocial factors. Consider referral to specialty as appropriate.</li> </ul> </li> </ul>  |
| <b>Service planning</b>   |   |

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| <b>Recommendations for service planning for long COVID</b> | <ul style="list-style-type: none"><li>■ In patients who have these symptoms, there should be appropriate assessment and initial symptomatic treatment and monitoring by primary care providers, with escalation of care to relevant multidisciplinary specialties if necessary, to determine diagnosis and management of organ injury, chronic fatigue syndrome (myalgic encephalomyelitis), dysautonomia, cognitive disturbance or psychological syndromes. (Level of evidence V, Grade of evidence D, Strength of recommendation Weak)</li></ul> |
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**Key:** CXR - chest X-ray; ECG - electrocardiogram; N/A - not applicable; N/R - not reported.

### Appendix 3.4 Data extraction table for Long Covid-19: Proposed Primary Care Clinical Guidelines for Diagnosis and Disease Management

| Clinical guideline and or model of care characteristics  |   |
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| <b>Endorsing Organisation</b>  | Catalan Society of Family and Community Medicine (CAMFiC)   |
| <b>Title</b>   | Long Covid-19: Proposed Primary Care Clinical Guidelines for Diagnosis and Disease Management   |
| <b>Country</b>   | Spain   |
| <b>Date Published</b>  | 20 April 2021   |
| <b>URL</b>   | <a href="https://doi.org/10.3390/ijerph18084350">https://doi.org/10.3390/ijerph18084350</a>   |
| <b>National or regional</b>  | International   |
| <b>Adapted from previous guidelines and or model of care?<br/>If so which guidelines and or model of care was it adapted from?</b> | Endorses a number of recommendations from the NICE/SIGN/RCGP guidelines but does not explicitly state these were adapted.   |
| <b>Update(s) planned (including dates)</b>   | N/R   |
| Definition and diagnosis   |   |
| <b>Definition of long COVID used in the guideline and or model of care</b>   | <p><b>The guideline used the term “Long COVID-19”, which includes both ongoing and post-COVID-19 syndrome according to the NICE definitions:</b></p> <ul style="list-style-type: none"> <li>▪ Ongoing symptomatic COVID-19 <ul style="list-style-type: none"> <li>○ Signs and symptoms of COVID-19 from 4 to 12 weeks not explained by an alternative diagnosis after protocolized study.</li> </ul> </li> <li>▪ Post-COVID-19 syndrome <ul style="list-style-type: none"> <li>○ Signs and symptoms that develop during or following an infection consistent with COVID-19, continue for &gt;12 weeks and are not explained by an alternative diagnosis. The term “syndrome” reflects the concurrence of a multisystem, fluctuating, and often overlapping clusters of signs and symptoms that, in some patients, may follow a relapsing-remitting pattern and that may change over time and affect any bodily system.</li> </ul> </li> </ul> |
| <b>Recommendations for diagnosis of long COVID</b>   | <p><b>Symptoms</b></p> <ul style="list-style-type: none"> <li>▪ Respiratory: <ul style="list-style-type: none"> <li>○ Cough</li> <li>○ Dyspnea</li> <li>○ Expectoration</li> <li>○ Chest pain</li> </ul> </li> </ul>  |

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|  | <ul style="list-style-type: none"><li>■ Constitutional:<ul style="list-style-type: none"><li>○ Fever</li><li>○ Fatigue</li><li>○ Chills/shivers</li><li>○ Wheezing</li><li>○ Syncope</li><li>○ Edema</li></ul></li><li>■ Rheumatic:<ul style="list-style-type: none"><li>○ Myalgia</li><li>○ Myalgia and or arthralgia</li><li>○ Arthralgia</li></ul></li><li>■ Otolaryngological:<ul style="list-style-type: none"><li>○ Sore throat</li><li>○ Dysgeusia</li><li>○ Anosmia</li><li>○ Rhinorrhea</li><li>○ Nasal congestion</li><li>○ Hemoptysis</li><li>○ Otagia</li></ul></li><li>■ Digestive complaints:<ul style="list-style-type: none"><li>○ Anorexia</li><li>○ Diarrhea</li><li>○ Nausea or vomiting</li><li>○ Abdominal pain</li><li>○ Weight loss &gt;5%</li></ul></li><li>■ Neurological:<ul style="list-style-type: none"><li>○ Confusion/altered consciousness</li><li>○ Headache</li><li>○ Behavioural disorder</li><li>○ Memory loss</li><li>○ Sleep disorders</li><li>○ Vertigo/dizziness</li></ul></li><li>■ Other:<ul style="list-style-type: none"><li>○ Dry syndrome</li><li>○ Hair loss</li><li>○ Conjunctivitis</li></ul></li></ul> |
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**Primary Care Planning for Patients with Long Covid-19**

- Care of patients with long COVID-19 should be structured in 3 consecutive visits according to the time from diagnosis of SARS-CoV-2 infection.
- The first primary care visit (V1) should be made from the 4<sup>th</sup> week after confirmation of the diagnosis of SARS-CoV-2 infection with a positive SARS-CoV-2 test (PCR, antigen or antibody) or after the start of signs and symptoms of COVID-19 in case laboratory test is unavailable (preferably between the 5<sup>th</sup> and 6<sup>th</sup> week, depending on availability and resources), and should last at least 30 min, with active support from nurses, including:
  - Personal background: The medical record may be relevant when analyzing long-term symptoms.
  - SARS-CoV-2 infection: Diagnostic confirmation of SARS-CoV-2 infection (date and microbiological test), symptoms and approximate onset dates, hospital admission and discharge dates, maximum oxygen requirements, ICU admission and duration, therapies received, and complications during admission should be recorded.
  - Physical examination: A complete physical examination, with measurement of vital signs and baseline oxygen saturation, should be made, paying special attention to assessing the oropharynx and cardiorespiratory system.
  - Laboratory studies: A basic first visit laboratory study should be made, supplemented according to individualized patient criteria.
  - Complementary tests: Lung parenchyma evaluation is essential in all patients with COVID-19. Chest X-ray in at least the 2 conventional projections is the conventional test, and allows for agile general evaluation, and is usually accessible urgently. However, in primary care, chest ultrasound should be used when possible, as it is very useful in evaluating pneumonia and its complications and in the differential diagnosis.
- The second visit (V2) should be made from week 8 (preferably between weeks 9 and 10, depending on availability and resources). The objective is to evaluate the results of the V1 tests, make a differential diagnosis with other post-COVID-19 situations, and apply the corresponding diagnostic algorithms to identify potential causes that reasonably explain the symptoms.
- The third visit (V3) should be made from week 12 (between week 13 and week 14 week, depending on availability and resources) to evaluate the evolution of long-term symptoms and re-evaluate possible causes using the corresponding diagnostic algorithms.

**Assessment of Individual Signs and Symptoms*****Fatigue***

- Diagnostic approach for patients with fatigue persisting >4 weeks after SARS-CoV-2 infection at V1 should include:
  - Specific clinical history: The history should record the onset date and specific questions about fatigue (symptoms and accompanying signs, concomitant psychosocial and emotional factors,

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|  | <p>related drugs, substance abuse, sleep disorders and exposure to toxins), pre-COVID-19 infection diseases possibly associated with chronic fatigue, organ-specific sequelae resulting from severe COVID-19 infection requiring hospital admission that may cause fatigue, and other current symptoms coexisting with fatigue.</p> <ul style="list-style-type: none"> <li>○ Specific assessments: Tests should include specific laboratory tests (chloride, bicarbonate, calcium, phosphate, muscle enzymes, plasma cortisol levels) and spirometry under safe conditions (<i>according to the recommendations given by The Italian Respiratory Society for lung function testing in the context of COVID-19</i>).</li> </ul> <p><b>Arthralgia</b></p> <ul style="list-style-type: none"> <li>▪ Diagnostic approach for patients with joint pain persisting &gt;4 weeks after SARS-CoV-2 infection at V1 should include: <ul style="list-style-type: none"> <li>○ Specific clinical history: Record date of onset of joint pain, type of pain (nociceptive, neuropathic or mixed), location, duration, modification with exercise or rest (factors that relieve, worsen or trigger it) and response to analgesia. Pre-COVID-19 diseases possibly associated with joint pain and current symptoms co-existing with arthralgia (especially chronic fatigue) should be evaluated.</li> <li>○ Specific assessments: Tests should include specific laboratory tests (uric acid, proteinogram, ANA, rheumatoid factor, complement C3 and C4 levels). If joint inflammation is suspected, joint ultrasound is indicated (or simple radiology if not available). Monitoring of inflammation (synovitis and enthesitis) and peripheral joint damage may be useful, although there are insufficient data to recommend a specific ultrasound evaluation system or its periodicity.</li> </ul> </li> </ul> <p><b>Myalgia</b></p> <ul style="list-style-type: none"> <li>▪ Diagnostic approach for patients with myalgia persisting &gt;4 weeks after SARS-CoV-2 infection at V1 should include: <ul style="list-style-type: none"> <li>○ Specific clinical history: Record the onset date, location, duration, modification with exercise or rest, factors that relieve, worsen or trigger myalgia, response to analgesia, pre-COVID-19 infections possibly associated with myalgia, and other current symptoms co-existing with myalgia (especially chronic fatigue and generalized pain).</li> <li>○ Specific assessments: The following specific laboratory tests should be added (proteinogram, creatine kinase, aldolase, lactate dehydrogenase, ANA, rheumatoid factor).</li> </ul> </li> </ul> <p><b>Chest pain</b></p> <ul style="list-style-type: none"> <li>▪ Diagnostic approach for patients with chest pain persisting &gt;4 weeks after SARS-CoV-2 infection at V1 should include: <ul style="list-style-type: none"> <li>○ Specific clinical history: Collect the date of onset, location, duration, triggers, modification with exercise or rest, accompanying symptoms, history of trauma or fall.</li> <li>○ Specific assessments: The following tests should be added: laboratory tests (troponins and CPK-MB depending on availability), electrocardiogram, chest ultrasound (shown to be useful in the</li> </ul> </li> </ul> |
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differential diagnosis of pleuritic pain to distinguish whether its origin is in the chest wall or lung surface), and spirometry (under safe conditions); chest CT evaluation may be considered.

### **Cough**

- Diagnostic approach for patients with cough persisting >4 weeks after SARS-CoV-2 infection at V1 should include:
  - Specific clinical history: Collect the date of onset and characteristics (mostly dry, irritating, nonproductive cough; in productive cough the sputum characteristics should be investigated). Possible organ-specific sequelae resulting from severe COVID-19 infection requiring hospital admission that may cause chronic coughing, and iatrogenic sequelae related to invasive maneuvers (post-intubation orotracheal, post-tracheostomy) should be evaluated. Current symptoms co-existing with cough, especially new-onset fever and dyspnea, and other alarming symptoms should be evaluated.
  - Specific assessments: Spirometry (under safe conditions) is advised.

### **Dyspnea**

- Diagnostic approach for patients with shortness of breath persisting >4 weeks after SARS-CoV-2 infection at V1 should include:
  - Specific clinical history: Collect the data of onset and characteristics. It is important to rule out acute onset and to evaluate an association with increased physical demand or dyspnea at rest and, especially, an association with other symptoms, such as chest pain. The modified Medical Research Council dyspnea scale may be administered. Organ-specific sequelae of severe COVID-19 infection requiring hospitalisation that may cause dyspnea, invasive maneuvers and techniques carried out during the acute episode and which may have been an iatrogenic cause of secondary dyspnea, should be ruled out. Current symptoms co-existing with dyspnea, especially new-onset fever, should be assessed.
  - Specific assessments: Additional laboratory tests should be added (troponins and CPK-MB, natriuretic peptides according to availability). Gasometry is recommended if baseline oxygen saturation is persistently decreased without known prior cause, respiratory functional tests (simple spirometry and diffusing capacity of carbon monoxide), chest radiology, and 6-minute walk test. CT or angio-CT should be considered.
  - Sudden-onset dyspnea (or baseline dyspnea flare-up) usually requires urgent attention, especially if associated with alarming symptoms, paying particular attention to respiratory superinfections, pulmonary thromboembolism (especially in patients with a history of hospitalisation and severity), post-COVID-19 heart failure and organizing pneumonia. Late development of new respiratory symptoms and opacities (>2 weeks after the first symptoms of COVID-19), especially if not detected in previous CT studies, may suggest post-viral organizing pneumonia (already described in patients with influenza virus infection).

### **Anosmia/Dysgeusia**

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|  | <ul style="list-style-type: none"> <li>▪ Diagnostic approach for patients with anosmia and or dysgeusia persisting &gt;4 weeks after SARS-CoV-2 infection at V1 should include: <ul style="list-style-type: none"> <li>○ Specific clinical history: Collect the date of onset and characteristics and rule out previous disease (especially ear, nose, throat and neurological).</li> <li>○ Specific assessments: A specific physical examination including a complete otolaryngological examination should be made.</li> </ul> </li> </ul> <p><b>Headache</b></p> <ul style="list-style-type: none"> <li>▪ Diagnostic approach for patients with headache persisting &gt;4 weeks after SARS-CoV-2 infection at V1 should include: <ul style="list-style-type: none"> <li>○ Specific clinical history: Collect the date of onset and the main features. Evaluate manifestations leading to the suspicion of an underlying organic disease. A prior diagnosis of headache or neurological disease, and current symptoms coexisting with headache, especially neurological symptoms, should be evaluated.</li> <li>○ Specific assessments: The examination should include blood pressure, temporal artery inspection and palpation in patients aged &gt;50 years, temporomandibular joint examination, cranial palpation (painful spots, paranasal sinus, examination of sensitive points and triggers) and a complete neurological assessment (level of consciousness and meningogenic signs, gait, dysmetria, Romberg test, facial asymmetry, fundoscopy).</li> </ul> </li> </ul> <p><b>Digestive signs and symptoms</b></p> <ul style="list-style-type: none"> <li>▪ Diagnostic approach for patients with digestive signs and symptoms persisting &gt;4 weeks after SARS-CoV-2 infection at V1 should include: <ul style="list-style-type: none"> <li>○ Specific clinical history: Collect the date of onset and main features, previous gastrointestinal disease and former and current treatments.</li> <li>○ Specific assessments: The following tests should be added: laboratory tests (pancreatic enzymes, anti-transglutaminase tissue immunoglobulin A), determination of occult blood in feces, abdominal ultrasound, and assess digestive endoscopy, functional studies, and food intolerance.</li> </ul> </li> </ul> <p><b>Other long-term signs and symptoms</b></p> <ul style="list-style-type: none"> <li>▪ A wide range of long-term symptoms have been reported, including general symptoms (fever, chills, intolerance to temperature changes), otolaryngologic symptoms (rhinitis, nasal congestion, tinnitus, vertigo, pain, oropharyngeal discomfort), neuropsychological symptoms (confusion or “mental fog”, concentration and sleep disorders, instability), dryness or conjunctivitis. As with other stressful life situations or major illnesses, COVID-19 can lead to temporary intense hair loss (telogen effluvium) weeks after acute disease. There is not sufficient information to propose specific approaches to most of these symptoms, which are heterogeneous, unaccompanied by alterations in complementary tests, and generally too nonspecific to be attributed to a specific organic involvement. If there are normal results in the appropriate diagnostic tests,</li> </ul> |
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|  | <p>most could be included in syndromic presentations related to chronic upper airway involvement (as with other respiratory viral infections) or central sensitivity syndromes (such as CFS and FM).</p> <p><b>Diagnostic Approach to Long Covid-19</b></p> <p><b>Differential Diagnosis</b></p> <ul style="list-style-type: none"> <li>▪ Before establishing a probable diagnosis of post-COVID-19 syndrome, a differential diagnosis with other post-COVID-19 situations should be made to identify potential causes that may reasonably explain the symptoms, such as: <ul style="list-style-type: none"> <li>▪ Cardiopulmonary sequelae: <ul style="list-style-type: none"> <li>○ Pulmonary sequelae</li> <li>○ Pleural involvement</li> <li>○ Myocarditis</li> <li>○ Pericardial effusion</li> <li>○ In these patients, multidisciplinary care is needed to coordinate primary and hospital care.</li> </ul> </li> <li>▪ Post-COVID-19 thrombosis</li> <li>▪ Post-COVID-19 immune-mediated manifestations <ul style="list-style-type: none"> <li>○ Arthritis</li> <li>○ Myositis</li> <li>○ Pancreatitis</li> <li>○ Other manifestations: Skin (perniosis), neurological (encephalitis, Guillain-Barré syndrome, myelitis), renal (tubulopathies, glomerulonephritis), hematological (idiopathic thrombocytopenic purpura, autoimmune hemolytic anemia), endocrine (thyroiditis, manifesting as clinical symptoms of thyrotoxicosis), and systemic autoimmune (lupus, vasculitis, sarcoidosis, Kawasaki disease) diseases have been reported in COVID-19 patients</li> </ul> </li> </ul> </li> </ul> <p><b>Diagnosis of Post-COVID-19 Syndrome</b></p> <ul style="list-style-type: none"> <li>▪ After ruling out the above-mentioned processes, a tentative diagnosis of ongoing COVID-19 in the second visit (V2) may be made, enabling the primary care team plan for V3, which will evaluate the evolution (whether symptoms still persist) and reassess possible causes of the long-term symptoms; if the symptoms persist and no etiology reasonably explains the persisting symptoms and complementary tests at V3 are unaltered, the diagnosis of post-COVID-19 syndrome is confirmed, and a diagnostic approach to post-COVID-19 syndromic presentations should be made.</li> </ul> |
| <b>Management and treatment</b>                                      |  |
| <b>Recommendations for treatment and or management of long COVID</b> | <p><b>Management of Patients with Post-COVID-19 Syndrome</b></p> <p><b>Long-term fatigue</b></p> <ul style="list-style-type: none"> <li>▪ If fatigue persists as the main symptom, compliance with the classification criteria for CFS should be evaluated. If the criteria are met, the diagnosis of CFS associated with COVID-19 (which will be confirmed when the criteria are still fulfilled at 6 months) is made and the protocol of referral to the corresponding</li> </ul>  |

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|   | <p>multidisciplinary unit is applied. In the case of noncompliance, evaluation of the loss of physical condition related to the pandemic and psychological factors is recommended, as are adapted guidelines to increase progressive resistance training, physical activity programs, etc.</p> <p><b>Long-term generalised pain</b></p> <ul style="list-style-type: none"> <li>When generalised pain persists as the main symptom, compliance with the classification criteria for CGP and FM should be evaluated. If positive, the diagnosis of CGP or FM associated with COVID-19 is established and the patient should be referred to the pain unit or rheumatology department, depending on availability or closeness. Other factors (loss of physical condition, psychological factors) should be evaluated if not.</li> </ul> <p><b>Long-term dyspnea</b></p> <ul style="list-style-type: none"> <li>When dyspnea persists as the main symptom, and after ruling out all complementary tests for alternative diseases, the so-called respiratory burn syndrome, or chronic inflammation of the respiratory tract (trachea, bronchi, bronchioles) may be hypothesised, and referral to pulmonology or otolaryngology considered.</li> </ul> <p><b>Long-term anosmia/dysgeusia</b></p> <ul style="list-style-type: none"> <li>In these patients, referral to otolaryngology for follow up and treatment using specific olfactory training therapies is recommended.</li> </ul> <p><b>Long-term headache</b></p> <ul style="list-style-type: none"> <li>There are no studies on the characteristics of long-term headache in COVID-19, but it could be included among the primary headaches, which are diagnosed according to symptoms in the absence of organic or structural alterations. Ruling out a central sensitization syndrome, and a possible neurology consultation are recommended.</li> </ul> <p><b>Long-term digestive signs and symptoms</b></p> <ul style="list-style-type: none"> <li>In cases of chronicity (duration &gt;3 months), ruling out central sensitization syndromes and evaluating referral to the digestive department are recommended.</li> </ul> <p><i>The guidelines endorse the key points for managing long COVID-19 proposed by the NICE guidelines, including giving advice and information on self-management of symptoms, self-monitoring at home (heart rate, blood pressure, pulse oximetry, sleep surveillance), a central role for multidisciplinary rehabilitation support (covering physical, psychological and psychiatric aspects) with occupational therapy, physiotherapy, clinical psychology and psychiatric therapy and rehabilitation medicine.</i></p> |
| <b>Service planning</b>   |  |
| <p><b>Recommendations for service planning for long COVID</b></p> | <ul style="list-style-type: none"> <li>Provision needed of additional, specific human resources to serve the group of patients with long COVID-19. To implement comprehensive multidisciplinary care, primary care centres should be provided with additional support staff in the main areas identified (rehabilitation, mental health) in order to avoid fragmented care.</li> <li>The care of patients with long COVID-19 should be structured in 3 consecutive visits according to the time from diagnosis of SARS-CoV-2 infection.</li> </ul>   |

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|  | <ul style="list-style-type: none"> <li>○ The first visit should be made from the 4<sup>th</sup> week after confirmation of the diagnosis of SARS-CoV-2 infection with a positive SARS-CoV-2 test (PCR, antigen or antibody) or after the start of signs and symptoms of COVID-19 in case laboratory test is unavailable (preferably between the 5<sup>th</sup> and 6<sup>th</sup> week, depending on availability and resources), and should last at least 30 min, with active support from nurses. The objective should be a history and examination and complementary tests to study the possible underlying causes of long symptoms.</li> <li>○ The second visit should be made from week 8 (preferably between weeks 9 and 10, depending on availability and resources). The objective is to evaluate the results of the V1 tests, make a differential diagnosis with other post-COVID-19 situations, and apply the corresponding diagnostic algorithms to identify potential causes that reasonably explain the symptoms.</li> <li>○ The third visit (V3) should be made from week 12 (between week 13 and week 14 week, depending on availability and resources) to evaluate the evolution of long-term symptoms and re-evaluate possible causes using the corresponding diagnostic algorithms.</li> </ul> |
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**Key:** ANA - antinuclear antibodies; CFS - chronic fatigue syndrome; CGP - chronic generalised pain; CPK-MB - creatine phosphokinase myocardial band; CT - computed tomography; FM - fibromyalgia; ICU - intensive care unit; NICE - National Institute for Health and Care Excellence; N/R – not reported; PCR - polymerase chain reaction; RCGP - Royal College of General Practitioners; SIGN - Scottish Intercollegiate Guidelines Network.

### Appendix 3.5 Data extraction table for Interim Guidance on Evaluating and Caring for Patients with Post-COVID Conditions

| Clinical guideline and or model of care characteristics   |  |
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| <b>Endorsing Organisation</b>   | Centres for Disease Control and Prevention   |
| <b>Title</b>  | Interim Guidance on Evaluating and Caring for Patients with Post-COVID Conditions  |
| <b>Country</b>  | US   |
| <b>Date Published</b>   | 22 September 2022  |
| <b>URL</b>  | <a href="https://www.cdc.gov/coronavirus/2019-ncov/hcp/clinical-care/post-covid-index.html">https://www.cdc.gov/coronavirus/2019-ncov/hcp/clinical-care/post-covid-index.html</a> .  |
| <b>National or regional</b>   | National   |
| <b>Adapted from previous guidelines and or model of cares?<br/>If so which guidelines and or model of care was it adapted from?</b> | N/A  |
| <b>Update(s) planned (including dates)</b>  | N/R  |
| Definition and diagnosis  |  |
| <b>Definition of long COVID used in the guideline and or model of care</b>  | <p><b>Post-COVID Conditions</b></p> <ul style="list-style-type: none"> <li>▪ CDC uses the term “post-COVID conditions” (PCC) as an umbrella term for the wide range of health consequences that can be present 4 or more weeks after infection with SARS-CoV-2, the virus that causes COVID-19.</li> <li>▪ CDC considers post-COVID conditions to be present if recovery does not occur after the 4-week acute phase even though many patients continue to recover between 4 and 12 weeks.</li> <li>▪ While patients may still recover after 12 weeks, persistent illness becomes more likely.</li> <li>▪ CDC uses the 4-week timeframe in describing post-COVID conditions to emphasize the importance of initial clinical evaluation and supportive care during the initial 4 to 12 weeks after acute COVID-19.</li> </ul> |
| <b>Recommendations for diagnosis of long COVID</b>  | <p><b>Symptoms commonly reported among people with post-COVID conditions</b></p> <ul style="list-style-type: none"> <li>▪ Dyspnea or increased respiratory effort</li> <li>▪ Fatigue</li> <li>▪ PEM and/or poor endurance</li> <li>▪ “Brain fog”, cognitive impairment</li> <li>▪ Cough</li> <li>▪ Chest pain</li> <li>▪ Headache</li> </ul>   |

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|  | <ul style="list-style-type: none"> <li>▪ Palpitations and/or tachycardia</li> <li>▪ Arthralgia</li> <li>▪ Myalgia</li> <li>▪ Paresthesia</li> <li>▪ Abdominal pain</li> <li>▪ Diarrhea</li> <li>▪ Insomnia and other sleep difficulties</li> <li>▪ Fever</li> <li>▪ Lightheadedness</li> <li>▪ Impaired daily function and mobility</li> <li>▪ Pain</li> <li>▪ Rash (e.g. urticaria)</li> <li>▪ Mood changes</li> <li>▪ Anosmia or dysgeusia</li> <li>▪ Menstrual cycle irregularities</li> </ul> <p><b>Suggested Workup for Post-COVID Conditions</b></p> <ul style="list-style-type: none"> <li>▪ The history of present illness should include the patient’s COVID-19 disease course, severity of illness, and treatments received. When possible, healthcare professionals should establish a timeline of when symptoms emerged during acute illness and afterwards.</li> <li>▪ Past medical history should include assessment for prior conditions that could impact the severity of COVID-19 disease, including but not limited to asthma, allergies, chronic obstructive pulmonary disease, interstitial lung disease, chronic kidney disease, diabetes mellitus, obesity, sleep disorders, prior autoimmune disease, mood disorders (e.g. anxiety or depression), trauma and stressor-related disorders (e.g. adjustment disorder or PTSD), hypertension, migraines, fibromyalgia, or chronic fatigue.</li> <li>▪ Social history should include assessment of the level of material and social supports and resources available to the patient (e.g. finances, employment, housing, and access to food) and their potential impact on the capacity of patients to access health and recuperation services. Healthcare professionals should establish the patient’s current and pre-infection level of activity (e.g. nature of work or school activities, activities of daily living) as well as screen for potential or known substance use disorder.</li> <li>▪ Post-COVID conditions involve multiple organ systems, thus a thorough physical examination should be completed. For patients who report previous infection with SARS-CoV-2, in addition to standard vital signs (i.e. blood pressure, heart rate, respiratory rate, pulse-oximetry, body temperature) and body mass index, healthcare professionals should evaluate ambulatory pulse-oximetry for individuals presenting with respiratory symptoms, fatigue, or malaise. Orthostatic vital signs should be evaluated for individuals reporting postural symptoms, dizziness, fatigue, cognitive impairment, or malaise.</li> </ul> |
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**System-based conditions reported following SARS-CoV2 infection**

- Cardiovascular:
  - myocarditis
  - heart failure
  - pericarditis
  - orthostatic intolerance (e.g. POTS)
- Pulmonary:
  - interstitial lung disease
  - reactive airway disease
- Renal:
  - chronic kidney disease
- Dermatologic:
  - alopecia
- Rheumatologic:
  - reactive arthritis
  - fibromyalgia
  - connective tissue disease
- Endocrine:
  - diabetes mellitus
  - hypothyroidism
- Neurologic:
  - transient ischemic attack/stroke
  - olfactory and gustatory dysfunction
  - sleep dysregulation
  - altered cognition
  - memory impairment
  - headache
  - weakness
  - neuropathy
- Psychiatric:
  - depression
  - anxiety
  - PTSD
  - psychosis
- Hematologic:
  - pulmonary embolism

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|  | <ul style="list-style-type: none"> <li>○ arterial thrombosis</li> <li>○ venous thromboembolism</li> <li>○ other hypercoagulability</li> <li>▪ Urologic: <ul style="list-style-type: none"> <li>○ incontinence</li> <li>○ sexual dysfunction</li> </ul> </li> <li>▪ Other: <ul style="list-style-type: none"> <li>○ weight loss</li> <li>○ dysautonomia</li> <li>○ vitamin D deficiency</li> <li>○ allergies and mast cell activation syndrome</li> <li>○ reactivation of other viruses</li> <li>○ pain syndromes</li> <li>○ progression of comorbid conditions</li> </ul> </li> </ul> <p><b>Laboratory testing</b></p> <ul style="list-style-type: none"> <li>▪ A basic panel of laboratory tests might be considered for patients with ongoing symptoms (including testing for non-COVID conditions that may be contributing to illness) to assess for conditions that may respond to treatment, until more information and evidence is available for specific laboratory testing for post-COVID conditions.</li> <li>▪ More specialised testing may not be needed in patients who are being initially evaluated for post-COVID conditions; however, expanded testing should be considered if symptoms persist for 12 weeks or longer. The absence of laboratory-confirmed abnormalities or the decision to forgo extensive laboratory testing should not lead to dismissing the possible impact of a patient’s symptoms on their daily function.</li> </ul> <p><b>Basic diagnostic laboratory testing to consider for patients with post-COVID conditions</b></p> <ul style="list-style-type: none"> <li>▪ Blood count, electrolytes, and renal function <ul style="list-style-type: none"> <li>○ complete blood count with possible iron studies to follow, basic metabolic panel, urinalysis</li> </ul> </li> <li>▪ Liver function <ul style="list-style-type: none"> <li>○ liver function tests or complete metabolic panel</li> </ul> </li> <li>▪ Inflammatory markers <ul style="list-style-type: none"> <li>○ C-reactive protein, erythrocyte sedimentation rate, ferritin</li> </ul> </li> <li>▪ Thyroid function <ul style="list-style-type: none"> <li>○ TSH and free T4</li> </ul> </li> <li>▪ Vitamin deficiencies <ul style="list-style-type: none"> <li>○ vitamin D, vitamin B12</li> </ul> </li> </ul> <p><b>More specialised diagnostic laboratory testing to consider for patients with post-COVID conditions</b></p> <ul style="list-style-type: none"> <li>▪ Rheumatological conditions</li> </ul> |
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|  | <ul style="list-style-type: none"> <li>○ antinuclear antibody, rheumatoid factor, anti-cyclic citrullinated peptide, anti-cardiolipin, and creatine phosphokinase</li> <li>■ Coagulation disorders <ul style="list-style-type: none"> <li>○ D-dimer, fibrinogen</li> </ul> </li> <li>■ Myocardial injury <ul style="list-style-type: none"> <li>○ troponin</li> </ul> </li> <li>■ Differentiate symptoms of cardiac versus pulmonary origin <ul style="list-style-type: none"> <li>○ B-type natriuretic peptide</li> </ul> </li> </ul> <p>* The specialized diagnostic tests should be ordered in the context of suggestive findings on history and physical examination (e.g. testing for rheumatological conditions in patients experiencing arthralgias).</p> <p><b>Other Assessment and Testing Tools</b></p> <ul style="list-style-type: none"> <li>■ Healthcare professionals should use caution when conducting exercise capacity testing in some patients, especially those with post-exertional malaise. For these patients and others who may not have the stamina for extended or lengthy assessments, modifications in the testing plan may also be needed. Exercise capacity tests should be scheduled for a dedicated follow-up appointment so that patients can prepare additional home supports. Ensuring that the testing circumstances best support the patient to perform maximally and then documenting this performance can create an objective reliable record of functional status that may be needed for assessment for other services or disability.</li> <li>■ Additional diagnostic testing should be guided by findings from the patient history and physical examination and results of previous diagnostic testing, and may include a chest x-ray, pulmonary function tests, electrocardiogram, or echocardiogram for persistent or new respiratory or cardiac concerns, although more evidence is needed to support the utility of specific imaging tests for evaluation of post-COVID conditions. For patients who may require imaging based on clinical findings, symptom management and a rehabilitation plan can often be initiated simultaneously with the imaging workup. In patients with normal chest x-rays and normal oxygen saturation, CT imaging of the chest might have lower yield for assessing pulmonary disease. In patients without an elevated D-dimer and compatible symptoms, CT pulmonary angiogram may be lower yield in the context of a pulmonary embolism workup. In patients with brain fog symptoms, MRI of the brain might not be revealing for pathologic findings in the absence of focal neurological deficits. Further caution may be exercised in ordering imaging in children without a high index of suspicion of pathology. More specialized (e.g. cardiac MRI) imaging studies might merit consultation with specialists.</li> </ul> <p><b>Selected assessment tools for evaluating people with post-COVID conditions</b></p> <ul style="list-style-type: none"> <li>■ Functional status and/or quality of life <ul style="list-style-type: none"> <li>○ patient-Reported Outcomes Measurement Information System (e.g. Cognitive Function 4a)</li> <li>○ post-Covid-19 Functional Status Scale</li> <li>○ EuroQol-5D</li> </ul> </li> <li>■ Respiratory conditions</li> </ul> |
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|   | <ul style="list-style-type: none"> <li>○ Modified Medical Research Council Dyspnea Scale</li> <li>■ Neurologic conditions             <ul style="list-style-type: none"> <li>○ Montreal Cognitive Assessment</li> <li>○ Mini Mental Status Examination</li> <li>○ Compass 31 (for dysautonomia)</li> <li>○ Neurobehavioral Symptom Inventory</li> </ul> </li> <li>■ Psychiatric conditions             <ul style="list-style-type: none"> <li>○ General Anxiety Disorder-7</li> <li>○ Patient Health Questionnaire-9</li> <li>○ PTSD Symptom Scale</li> <li>○ Screen for Posttraumatic Stress Symptoms</li> <li>○ Checklist for DSM-5 (PCL-5)</li> <li>○ Impact of Event Scale-Revised</li> <li>○ Hospital Anxiety and Depression Scale</li> </ul> </li> <li>■ Other conditions             <ul style="list-style-type: none"> <li>○ Wood Mental Fatigue Inventory</li> <li>○ Fatigue Severity Scale</li> <li>○ Insomnia Severity Index</li> <li>○ Connective Tissue Disease Screening Questionnaire</li> </ul> </li> </ul> <p><b>Selected functional and other testing tools for evaluating people with post-COVID conditions</b></p> <ul style="list-style-type: none"> <li>■ Exercise capacity             <ul style="list-style-type: none"> <li>○ 1-minute sit-to-stand test</li> <li>○ 2-minute step test</li> <li>○ 10 Meter Walk Test</li> <li>○ 6-minute walk</li> </ul> </li> <li>■ Balance and fall risk             <ul style="list-style-type: none"> <li>○ BERG Balance Scale</li> <li>○ Tinetti Gait and Balance Assessment Tool</li> </ul> </li> <li>■ Other             <ul style="list-style-type: none"> <li>○ Tilt-table testing (e.g. for POTS)</li> <li>○ Orthostatic HR assessment</li> </ul> </li> </ul> |
| <b>Management and treatment</b>   |  |
| <p><b>Recommendations for treatment and or management of long COVID</b></p> | <p><b>Management of Post-COVID Conditions</b></p> <ul style="list-style-type: none"> <li>■ For most patients, the goal of medical management of post-COVID conditions is to optimize function and quality of life. Ideally, healthcare professionals, in consultation with the appropriate specialists, should develop a comprehensive management plan based on their patients’ presenting symptoms, underlying</li> </ul>   |

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|  | <p>medical and psychiatric conditions, personal and social situations, and their treatment goals. Setting achievable goals through shared decision-making can be beneficial. Transparency is important for the process of goal setting; healthcare professionals should advise patients that post-COVID conditions are not yet well understood, and assure them that support will continue to be provided as new information emerges. Healthcare professionals and patients should continue to discuss progress and challenges and reassess goals as needed. Symptoms not explained by, or out of proportion to, objective findings are not uncommon after COVID-19 and should not be dismissed even if there is not yet a full understanding of their etiology or their expected duration.</p> <ul style="list-style-type: none"> <li>■ Many post-COVID conditions can be improved through already established symptom management approaches (e.g. breathing exercises to improve symptoms of dyspnea). Creating a comprehensive rehabilitation plan may be helpful for some patients and might include physical and occupational therapy, speech and language therapy, vocational therapy, as well as neurologic rehabilitation for cognitive symptoms. A conservative physical rehabilitation plan might be indicated for some patients (e.g. persons with post-exertional malaise); consultation with physiatry for cautious initiation of exercise and recommendations about pacing may be useful. Gradual return to exercise as tolerated could be helpful for most patients. Optimizing management of underlying medical conditions might include counseling on lifestyle components such as nutrition, sleep, and stress reduction (e.g. meditation).</li> <li>■ Patient diaries and calendars might be useful to document changes in health conditions and symptom severity, especially in relation to potential triggers such as exertion (physical and cognitive), foods, menstruation, and treatments or medications. Such diaries and calendars can provide greater insight into patients' symptoms and lived experience for healthcare professionals. Healthcare professionals should encourage patients to report any new or changing symptoms and to discuss any changes in activities or routines.</li> <li>■ Patients with post-COVID conditions may share some of the symptoms that occur in patients who experience myalgic encephalomyelitis/chronic fatigue syndrome, fibromyalgia, post-treatment Lyme disease syndrome, dysautonomia and mast cell activation syndrome. Symptom management approaches that have been helpful for these disorders may also benefit some patients with post-COVID conditions (e.g., activity management (pacing) for post-exertional malaise).</li> <li>■ FDA-approved or over the counter medications as well as vitamin or electrolyte supplements may be helpful for indicated illnesses (e.g. headache, anxiety) or documented deficiencies (e.g. vitamin deficiency) after carefully weighing the benefits and risks of pharmaceutical interventions. Some treatments have been offered that lack evidence of efficacy or effectiveness, and could be harmful to patients. Healthcare professionals should inquire about any unprescribed medications, herbal remedies, supplements, or other treatments that patients may be taking for their post-COVID conditions.</li> <li>■ Follow-up visits with a healthcare professional might be considered every 2–3 months, with frequency adjusted up or down depending on the patient's condition and illness progression.</li> </ul> |
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**Holistic Support for Patients with Post-COVID Conditions**

- Evidence indicates that holistic support for the patient throughout their illness course can be beneficial. Recognising and validating the impact of illness on quality of life should be part of the ongoing healthcare professional and patient interaction. Healthcare professionals can provide information on peer support resources (e.g. patient support groups, online forums). Support groups are connecting individuals, providing support, and sharing resources for persons affected by COVID-19. When material, employment or other social support needs are identified, healthcare professionals should consider referral themselves (if they are knowledgeable and able) and engaging a social worker, case worker, community health worker, or similarly trained professional to assist.

**General Post-COVID Care Considerations**

- For most patients with possible post-COVID conditions, healthcare professionals might choose a conservative diagnostic approach in the first 4 to 12 weeks following SARS-CoV-2 infection. Laboratory and imaging studies can often be normal or nondiagnostic in patients experiencing post-COVID conditions and symptoms may improve or resolve during the first few months after acute infection in some patients, further supporting an initial conservative approach to diagnostic testing. However, workup and testing should not be delayed when there are signs and symptoms of urgent and potentially life-threatening clinical conditions (e.g. pulmonary embolism, myocardial infarction, pericarditis with effusion, stroke, renal failure). Symptoms that persist beyond 3 months should prompt further evaluation.
- Most post-COVID conditions can be diagnosed and managed by primary care providers, and a patient-centered medical home model could be helpful, with coordinated comprehensive care and open communication among a core group of specialty care providers and support services (e.g., occupational therapy, physical therapy, social work) to maximise functional improvement and rehabilitation efforts. Healthcare professionals may also consider referral to multidisciplinary post-COVID care centers, where available, for additional care considerations. Multidisciplinary post-COVID care centers based in a single physical location can provide a comprehensive and coordinated treatment approach to COVID-19 aftercare. Based on clinical evaluation and response to treatment, healthcare professionals might consider using a stepwise approach to other specialist referrals. Healthcare professionals should be mindful of the additional burden (e.g., financial, time, and psychological burden) multiple specialist visits may place on patients and the possibility of fragmented care that can increase the risk of contradictory medical advice.
- Approaches that incorporate telemedicine, including phone calls and virtual visits, can be helpful for ongoing follow-up and might lessen the burden on patients with limited energy from post-COVID conditions or who have other concerns about in-person visits. Although an in-person initial assessment might be ideal, under some circumstances it may not be possible. Evaluation and care should not be delayed if only telemedicine options are available.

**Effective post-COVID care might include:**

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|  | <ul style="list-style-type: none"> <li>▪ Providing holistic patient-centered management approaches to improve patient quality of life and function and partnering with patients to identify achievable health goals.</li> <li>▪ Facilitating standardised, trauma-informed approaches to assessing symptoms and conditions.</li> <li>▪ Setting expectations with patients and their families that outcomes from post-COVID conditions differ among patients. Some patients may experience symptom improvement within the first 3 months, whereas others may continue to experience prolonged symptoms.</li> <li>▪ Continuing follow-up over the course of illness, with considerations of broadening the testing and management approach over time if symptoms do not improve or resolve, while remaining transparent that there is much more to learn about post-COVID conditions.</li> <li>▪ Establishing partnerships with specialists for physical and mental healthcare, when needed, which may include comprehensive rehabilitation services.</li> <li>▪ Connecting patients to social services when available, including assistance for other hardships (e.g. financial, family illness, bereavement, caregiving) and resources on disability and reasonable accommodations for work or school, and connections to patient support groups.</li> </ul> |
| <b>Service planning</b>                                    |  |
| <b>Recommendations for service planning for long COVID</b> | N/R  |

**Key:** CT - computed tomography; MRI - magnetic resonance imaging; N/A - not applicable; N/R – not reported; PASC - post acute sequelae of SARS-CoV-2 infection; PEM - post exertional malaise is the worsening of symptoms following even minor physical or mental exertion, with symptoms typically worsening 12 to 48 hours after activity and lasting for days or even weeks; POTS - postural orthostatic tachycardia syndrome; PTSD - post traumatic stress disorder.

**Appendix 3.6 Data extraction table for Interim guidance on Long-COVID management principles**

| <b>Clinical guideline and or model of care characteristics</b>   |  |
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| <b>Endorsing Organisation</b>  | Istituto Superiore di Sanita   |
| <b>Title</b>   | Interim guidance on Long-COVID management principles   |
| <b>Country</b>   | Italy  |
| <b>Date Published</b>  | 1 July 2021  |
| <b>URL</b>   | <a href="https://www.iss.it/documents/20126/0/Rapporto+ISS+COVID-19+n.15_2021_EN.pdf/dd962ad9-fa53-73dd-7759-55cb5c167675?t=1627575304593">https://www.iss.it/documents/20126/0/Rapporto+ISS+COVID-19+n.15_2021_EN.pdf/dd962ad9-fa53-73dd-7759-55cb5c167675?t=1627575304593</a>  |
| <b>National or regional</b>  | National   |
| <b>Adapted from previous guidelines and or model of care?<br/>If so which guidelines and or model of care was it adapted from?</b> | The report acknowledges the recommendations on the subject of long-COVID provided by the WHO and adapts them to the Italian situation.<br>Self-Management; NICE guidelines   |
| <b>Update(s) planned (including dates)</b>   | N/R  |
| <b>Definition and diagnosis</b>  |  |
| <b>Definition of long COVID used in the guideline and or model of care</b>   | <p><b>Long-COVID includes both the persistent symptomatic form and the post-COVID syndrome</b></p> <ul style="list-style-type: none"> <li>This condition is therefore characterised by signs and symptoms caused by the SARS-CoV-2 infection that continue or develop after 4 weeks from an acute infection. The use of a shared terminology provides a basis for the programming of services to be provided, it facilitates the delivery of care and makes it possible to define a set of clinical data that are necessary for monitoring and research.</li> </ul> <p><b>Persistent symptomatic COVID-disease</b></p> <ul style="list-style-type: none"> <li>NICE definition: Signs and symptoms attributable to COVID-19 lasting between 4 and 12 weeks after the acute event.</li> </ul> <p><b>Post-COVID-19 syndrome</b></p> <ul style="list-style-type: none"> <li>NICE definition: Signs and symptoms that developed during or after an infection compatible with COVID-19, present for more than 12 weeks after the acute event and that cannot be explained by alternative diagnoses.</li> </ul> |
| <b>Recommendations for diagnosis of long COVID</b>   | <p><b>Possible clinical manifestations:</b></p> <p><b>General</b></p> <ul style="list-style-type: none"> <li>Persistent fatigue/Asthenia</li> <li>Excessive tiredness</li> <li>High temperature</li> </ul>   |

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|  | <ul style="list-style-type: none"> <li>▪ Muscle weakness</li> <li>▪ Diffuse pain</li> <li>▪ Myalgia</li> <li>▪ Arthralgia</li> <li>▪ Worsened perception of health conditions</li> <li>▪ Anorexia, decreased appetite</li> <li>▪ Sarcopenia</li> </ul> <p><b><i>Organ-specific</i></b></p> <ul style="list-style-type: none"> <li>▪ Pulmonary: <ul style="list-style-type: none"> <li>○ dyspnoea/Shortness of breath</li> <li>○ persistent cough</li> </ul> </li> <li>▪ Cardiovascular: <ul style="list-style-type: none"> <li>○ chest tightness</li> <li>○ chest pain</li> <li>○ palpitations</li> <li>○ tachycardia</li> <li>○ arrhythmias</li> <li>○ variations in arterial pressure</li> </ul> </li> <li>▪ Neurological</li> </ul> <p><i>Manifestations of the central nervous system</i></p> <ul style="list-style-type: none"> <li>○ headache (often unresponsive to analgesics)</li> <li>○ cognitive impairment (brain fog)</li> <li>○ difficulties in concentrating and attention</li> <li>○ memory problems</li> <li>○ difficulties in executive functions</li> <li>○ dizziness</li> <li>○ sleep disorders</li> <li>○ dysautonomia (postural hypotension)</li> </ul> <p><i>Manifestations of the peripheral nervous system</i></p> <ul style="list-style-type: none"> <li>○ tingling and numbness (peripheral neuropathies)</li> <li>○ loss of taste and smell</li> </ul> <p><i>Rare neurological manifestations</i> (complications in the acute phase of the COVID-19 infection which could entail permanent neurological damage)</p> <ul style="list-style-type: none"> <li>○ acute cerebrovascular events (ischemic / haemorrhagic stroke)</li> <li>○ seizures</li> <li>○ meningitis/encephalitis</li> </ul> |
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|  | <ul style="list-style-type: none"><li>○ myelopathy/myelitis</li><li>○ Guillain-Barré syndrome, Miller Fisher syndrome, cranial polyneuritis, demyelinating disease of the central nervous system</li><li>■ Psychiatric/ psychological:<ul style="list-style-type: none"><li>○ depression</li><li>○ anxiety</li><li>○ PTSD</li><li>○ obsessive-compulsive symptoms</li><li>○ delirium (in the elderly)</li><li>○ psychosis</li></ul></li><li>■ Gastrointestinal:<ul style="list-style-type: none"><li>○ abdominal pain</li><li>○ nausea</li><li>○ vomiting</li><li>○ diarrhoea</li><li>○ dyspepsia</li><li>○ belching</li><li>○ gastroesophageal reflux</li><li>○ abdominal distension</li></ul></li><li>■ Ear, Nose and Throat:<ul style="list-style-type: none"><li>○ tinnitus</li><li>○ earache</li><li>○ sore throat (pharyngodynia)</li><li>○ difficulty in swallowing (dysphagia)</li><li>○ dysphonia</li></ul></li><li>■ Dermatological:<ul style="list-style-type: none"><li>○ erythema pernio</li><li>○ papulo-squamous disorder</li><li>○ morbilliform rash</li><li>○ urticarial eruptions</li><li>○ alopecia</li></ul></li><li>■ Haematological:<ul style="list-style-type: none"><li>○ thromboembolism</li></ul></li><li>■ Kidney:<ul style="list-style-type: none"><li>○ haematuria and proteinuria (nephropathy)</li></ul></li></ul> |
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|  | <ul style="list-style-type: none"> <li>▪ Endocrine:             <ul style="list-style-type: none"> <li>○ new-onset Diabetes mellitus and subacute thyroiditis</li> </ul> </li> <li>▪ Long-COVID must be distinguished from the Post-Intensive Care Syndrome, which is characterised by impaired lung function, neuromuscular weakness, long-term psychological disorders and reduced quality of life. This condition is common among people with severe acute infections who have spent a long time in intensive care and may coexist with Long-COVID in some cases.</li> </ul> <p><b>Multidimensional evaluation</b></p> <ul style="list-style-type: none"> <li>▪ In view of the wide range of symptoms and conditions that characterize Long-COVID, the evaluation of patients with this condition needs to be multidimensional and include numerous clinical, functional, cognitive, psychological and nutritional aspects.</li> <li>▪ It is of fundamental importance to obtain:             <ul style="list-style-type: none"> <li>○ A full medical history including:                 <ul style="list-style-type: none"> <li>• history of acute COVID-19 (suspected or confirmed)</li> <li>• nature and severity of previous and current symptoms</li> <li>• timing and duration of symptoms from the onset of acute COVID-19</li> <li>• history of other health conditions</li> <li>• current and previous drug treatment</li> </ul> </li> <li>○ An evaluation of the specific signs and symptoms of Long-COVID.</li> <li>○ An assessment of how the person’s activities, e.g. work or education, mobility, independence and functional status (activities of daily living), lifestyle have been affected by Long-COVID.</li> <li>○ An assessment of the psychological impact of COVID-19 and Long-COVID, with particular attention to the onset of symptoms of anxiety, depression and social isolation.</li> <li>○ An assessment of the impact of COVID-19 and Long-COVID on nutritional aspects, changes in body weight and loss of interest in eating and drinking, particularly in the elderly.</li> <li>○ An assessment of the presence of new cognitive symptoms or brain fog, using a validated screening tool to assess the patients’ cognitive status.</li> </ul> </li> </ul> |
| <b>Management and treatment</b>                                      |  |
| <b>Recommendations for treatment and or management of long COVID</b> | <b>Multidisciplinary approach</b>  |



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|  | <ul style="list-style-type: none"> <li>▪ Management of patients with Long-COVID in order to be able to respond to the different clinical, functional, cognitive, psychological and nutritional manifestations of the disorder. This approach is to be personalised, modulated and adapted by keeping account of the variety of conditions that may arise in individual patients.</li> <li>▪ Some selected patients may be put on multidisciplinary rehabilitation programs that take of account the physical, psychological and psychiatric aspects of rehabilitation. These programs must: <ul style="list-style-type: none"> <li>○ Be based on a multidimensional assessment of the person's condition with the development of tailored rehabilitation plans.</li> <li>○ Involve a multidisciplinary team which, in addition to the medical doctor, includes an occupational therapist, a physiotherapist and a psychologist.</li> <li>○ Provide specific specialist skills in the treatment of fatigue and respiratory symptoms (including dyspnoea).</li> </ul> </li> <li>▪ It is important to define timely and personalised follow-ups tailored to the characteristics and needs of each patient in order to re-evaluate the general conditions and plan new interventions if necessary.</li> </ul> <p><b>Self-management</b></p> <ul style="list-style-type: none"> <li>▪ Provide information and training on self-management to patients with Long-COVID, starting with the initial evaluation. This should include: <ul style="list-style-type: none"> <li>○ Self-management of symptoms, setting realistic goals</li> <li>○ Indication of people to contact in case of deterioration or need for support</li> <li>○ Information on possible sources of support, including support groups, social services, online forums, Apps</li> <li>○ Information on ways of obtaining support from other services including social services, accommodation services and advice on financial support</li> <li>○ Information about the new and persistent symptoms of COVID-19 that the patient can share with family members, caregivers and friends</li> </ul> </li> <li>▪ Provide patient support for interviews with their employer, school or university regarding return to work or teaching activities, e.g. by providing for a gradual resumption of activities.</li> </ul> |
| <b>Service planning</b>                                    |  |
| <b>Recommendations for service planning for long COVID</b> | <p><b>Multidisciplinary approach</b></p> <ul style="list-style-type: none"> <li>▪ The structuring of the care should be led by a doctor with expertise and experience in COVID-19 (e.g. GP, pneumologist, geriatrician, infectious disease specialist, internist), there should be appropriate specialist support and local programs in which primary and specialist care are integrated, as well as multidisciplinary and hospital rehabilitation services.</li> <li>▪ Based on patient conditions and on local availability, the specific services can be delivered through a one-stop assessment (i.e. concentrating the consultation with the various specialists and the diagnostic tests on a single day, for instance in a Long-COVID day hospital), which is preferable in elderly or frail patients, or</li> </ul>  |

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|  | <p>staggered over time. The treatment program must also include a follow-up adapted to the characteristics of the patient</p> <ul style="list-style-type: none"> <li>▪ The care envisaged for Long-COVID patients characterised by low clinical complexity can be coordinated and managed by the GP. More complex patients, treatment can be managed in another context (e.g. hospital), as long as there is always direct contact with the GP who is treating the patient. In order to coordinate the delivery of care in the more complex cases, the family or community nurse can be used.</li> </ul> <p><b>Primary care for patients with LONG-COVID should be structured on 3 levels:</b></p> <p><b>1. Stratification of the groups of patients at risk of developing Long-COVID</b><br/>It is very important that patients with a history of COVID-19 be followed up even after a negative swab. In particular, maximum attention must be paid to the more frail, immunosuppressed, elderly patients with multiple comorbidities who have been previously hospitalised for COVID-19 or who have developed significant symptoms during the disease. In all these cases, the GP must continue to take care of the patient considering a follow-up (including periodic phone calls), and carry out a multidimensional assessment if a clinical picture compatible with Long-COVID occurs.</p> <p><b>2. Evaluation of patients with Long-COVID-like symptoms</b><br/>The evaluation should be based on a holistic approach that investigates general, cognitive and psychological symptoms along with an integrated socio-health evaluation. Blood tests as well as radiological, ultrasound and functional tests, modulated according to the patients' conditions, need to be carried out, and functional tests are to be performed to see whether and to what extent the patient's daily life and activities (e.g. work, mobility, degree of autonomy, well-being and social life) are affected by the post-COVID-19 syndrome. This type of assessment is within the mission and task of the GP with the contribution of specialty doctors, including psychologists where necessary.</p> <p><b>3. Planning of care pathways</b><br/>Once other causes have been excluded, patients could be included in a multidisciplinary program that also involves other specialists and allows for a patient-centred approach. Finally, it is important for this purpose to provide advice on self-management to patients with Long-COVID to help them manage their symptoms, providing them with information on the healthcare services they need to contact in case their symptoms worsen, and make appointments for regular follow-up exams in order to monitor their clinical performance. This can be done also through telemedicine tools such as tele-consultation, tele-visits and other tele-health systems that are useful for monitoring instrumental and non-instrumental data.</p> <p><b>Examples of Regional Model of Care:</b><br/><b>Emilia-Romagna Region-pneumonia specific</b><br/>Three scenarios of reference are envisaged:</p> <ul style="list-style-type: none"> <li>▪ Patients with a previous positive swab who are currently asymptomatic, regardless of the symptoms they had in the acute phase. A follow-up program for these patients has not been envisaged except in the context of research protocols.</li> </ul> |
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|  | <ul style="list-style-type: none"> <li>▪ Symptomatic patients (PCPS) and patients with a clinical history attributable to the SARS-CoV-2 infection with or without confirmation of organ involvement (in any case &lt;30-40% of the lung parenchyma).</li> <li>▪ The program foresees that the patient be examined at a general medicine outpatient clinic; where required, the doctor may directly perform or request additional first level examinations, or request a pneumology or internal / geriatric examination, a neurocognitive screening or quality of life assessment to be performed during the medical examination; the GP examines the patient within 3-6 months of hospital discharge or once the acute phase is over and evaluates the priority criteria through triage that may even be done over the telephone; further investigations are managed directly by dedicated specialist clinics.</li> <li>▪ Symptomatic patients (PCPS) and previous interstitial pneumonia with extensive organ involvement (&gt; 30-40% of the lung parenchyma) and / or patients who have undergone steroid therapy in the acute phase and / or patients discharged who are on oxygen therapy. These patients always have access to the specialist outpatient clinics where the multidisciplinary / multiprofessional teams have been set up in the local healthcare units: the specialist in charge of the patient initiates the diagnostic evaluation involving other professionals identified on the basis of the organ impairment of each patient; access to the specialist outpatient clinic is provided through an appointment made directly by the specialist at the time of discharge or through a request by the GP; the first follow-up visit at the specialist clinic must take place within 3-6 months after discharge of the patient from the hospital.</li> </ul> <p><b>Abruzzi Region</b></p> <ul style="list-style-type: none"> <li>▪ The specific regional program envisages the establishment of the Long-COVID Outpatient Clinics.</li> <li>▪ In order to classify the patients with sequelae of COVID-19 disease, with particular attention to the respiratory function and to any other problem of specialist interest, the specialist in infectious diseases will use a specific screening questionnaire that can be administered also by telephone, to investigate, in particular, the presence of persistent symptoms that continue for more than 12 weeks after recovery from COVID-19 and that cannot be explained by an alternative diagnosis.</li> <li>▪ Patients who were treated at home or in long-term healthcare facilities during the acute phase may be contacted directly by the GPs or by the USCA doctors to begin the follow-up through an interview.</li> </ul> <p><b>Tuscany Region</b></p> <ul style="list-style-type: none"> <li>▪ Tuscany Region approved the regional guidelines for the delivery of care to all the people who have had a COVID-19-related clinical picture, and for the definition of the operational protocol for the clinical follow-up of COVID-19 patients who are clinically cured.</li> <li>▪ The protocol establishes a program of continuous clinical care aimed at identifying and treating the outcomes deriving from COVID-19 through a multidisciplinary and personalised approach, in order to identify any early physical, psychological and neurocognitive outcomes that are a consequence of the SARS-CoV-2 infection.</li> <li>▪ Patients who during the acute phase were hospitalised in a hospital ward in Tuscany for COVID-19, are contacted by the hospital where they were hospitalised, and the GPs are involved for sharing and</li> </ul> |
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|  | <p>subsequent management. Patients who were managed at home or in social healthcare facilities during the acute phase are contacted directly by the GPs to start the follow-up activities.</p> <ul style="list-style-type: none"> <li>▪ First step, to be completed within 2 months from clinical recovery, consists of a clinical questionnaire, from which it is possible to infer whether any problems emerged after recovering, and the performance of the blood tests envisaged in the basic protocol (access to this service is organized by the health local units and the process is explained to the patient at the time of first contact). The questionnaire can be administered by healthcare personnel, doctors or nurses or, depending on the case, delivered to the patient or family by the GP / Primary Care Paediatrician. The information is evaluated and integrated with details from the patient's history by the reference doctor of the follow-up program (hospital specialist, GP / Primary Care Paediatrician, depending on whether the patient is hospitalised or not), preferably through a remote examination.</li> <li>▪ In relation to the problems that have emerged, the reference doctor for the follow-up may identify the need for an urgent specialist check-up, which can be requested with the exemption code that identifies COVID-19 patients (P01), or activate a personalised day-service program in accordance with the multidisciplinary and multi-organ approach and continuity of the treatment program.</li> <li>▪ A second step is envisaged for patients who have been hospitalised or who are referred to a specialist during the first step. In the second step, the controls, the multidisciplinary and multiprofessional assessments, the blood tests and the instrumental tests are extended up to 12 months after the acute phase of the COVID-19 disease.</li> </ul> |
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**Key:** GPs - general practitioners; NICE - National Institute for Health and Care Excellence; N/R – not reported; PCPS - post COVID pneumonia syndrome; PTSD – post traumatic stress disorder; WHO - World Health Organization.

**Appendix 3.7 Data extraction table for Post-COVID-19 Conditions in Children and Adolescents**

| <b>Clinical guideline and or model of care characteristics</b>   |  |
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| <b>Endorsing Organisation</b>  | American Academy of Pediatrics   |
| <b>Title</b>   | Post-COVID-19 Conditions in Children and Adolescents   |
| <b>Country</b>   | US   |
| <b>Date Published</b>  | 28 July 2021   |
| <b>URL</b>   | <a href="https://www.aap.org/en/pages/2019-novel-coronavirus-covid-19-infections/clinical-guidance/post-covid-19-conditions-in-children-and-adolescents">https://www.aap.org/en/pages/2019-novel-coronavirus-covid-19-infections/clinical-guidance/post-covid-19-conditions-in-children-and-adolescents</a>  |
| <b>National or regional</b>  | National   |
| <b>Adapted from previous guidelines and or model of care?<br/>If so which guidelines and or model of care was it adapted from?</b> | Adapted from CDC interim guidance  |
| <b>Update(s) planned (including dates)</b>   | Last updated on 2 September 2022. Guidance will be regularly reviewed with regards to the evolving nature of the pandemic and emerging evidence. Will be presumed to expire on December 31, 2022.  |
| <b>Definition and diagnosis</b>  |  |
| <b>Definition of long COVID used in the guideline and or model of care</b>   | <ul style="list-style-type: none"> <li>▪ The post-COVID-19 condition is an umbrella term that encompasses physical and mental health consequences experienced by some patients that are present 4 or more weeks following a SARS-CoV-2 illness.</li> <li>▪ WHO consensus definition for pediatric PASC is also given: The presence of one or more new, persistent physical symptoms, which may fluctuate and relapse, that lasts at least 12 weeks after confirmed initial SARS-CoV-2 infection and impairs daily function.</li> </ul>   |
| <b>Recommendations for diagnosis of long COVID</b>   | <p><b>Common Symptoms</b></p> <p><b>Respiratory</b></p> <ul style="list-style-type: none"> <li>▪ Chest pain, cough, and exercise-induced dyspnea.</li> <li>▪ Chest imaging is needed for persistent respiratory symptoms or patients who had pulmonary abnormality identified during the acute infection.</li> <li>▪ Children 6 years or older who have persistent symptoms should receive pulmonary function testing.</li> <li>▪ For any patient with persistent exercise-induced dyspnea after initial cardiopulmonary evaluation, including evaluation for thromboembolic disease and heart disease, cardiopulmonary exercise testing can be performed to assess for deconditioning or pulmonary/cardiac limitation under stress.</li> </ul> <p><b>Cardiac</b></p> <ul style="list-style-type: none"> <li>▪ Chest pain and shortness of breath (sign of myocarditis), arrhythmias and fatigue.</li> </ul> |

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|  | <p><b>Anosmia and/or Ageusia</b></p> <ul style="list-style-type: none"> <li>▪ Symptom report can be challenging in very young children, but reduced oral intake, changes in feeding behaviors, or gagging with/avoidance of previously well-tolerated food could indicate changes in smell or taste resulting from COVID-19.</li> <li>▪ Persistent anosmia warrants further evaluation, nutrition optimization, olfactory testing, and potentially olfactory training.</li> </ul> <p><b>Neurodevelopmental</b></p> <ul style="list-style-type: none"> <li>▪ Changes or delays in cognitive, language, academic, motor or mood/behavioral domains.</li> <li>▪ An age-specific history and evaluation for neurodevelopmental impairment is recommended to assess any changes or delays in cognitive, language, academic, motor, or mood/behavioral domains.</li> </ul> <p><b>Cognitive Fogginess or Fatigue</b></p> <ul style="list-style-type: none"> <li>▪ "Brain fog" refers to unclear or "fuzzy" thinking, inattention, difficulty with concentration or memory</li> <li>▪ These changes can manifest as inattentiveness, seeming to be more forgetful to a parent, slower in reading or processing, requiring more repetition in learning, less endurance and/or requiring more breaks when reading or performing other cognitive tasks, etc.</li> <li>▪ For cognitive complaints that persist and result in functional impairment, a targeted neuropsychological evaluation can identify the basis for these symptoms and guide the development of an appropriate, often multidisciplinary, treatment plan.</li> </ul> <p><b>Physical Fatigue/Poor Endurance</b></p> <ul style="list-style-type: none"> <li>▪ Following SARS-CoV-2 infection, children and adolescents may complain of easy fatigability and poor endurance even without known cardiac and respiratory involvement. Cardiac evaluation should be performed for patients with significant fatigue who also demonstrate any "red flag" cardiac symptoms, such as syncope, radiating chest pain, or chest pain with exertion, prior to return to any exercise.</li> </ul> <p><b>Headache</b></p> <ul style="list-style-type: none"> <li>▪ The history, evaluation, and management are the same as any child presenting with headache evaluating for "red flag" characteristics, associated neurologic findings, and other possible causes of headache.</li> <li>▪ Red flag characteristics: <ul style="list-style-type: none"> <li>○ focal or side-locked headache,</li> <li>○ vomiting that is persistent or worsening</li> <li>○ focal neurologic symptoms</li> </ul> </li> <li>▪ Causes of post-COVID-19 headache may be most related to situational factors such as: <ul style="list-style-type: none"> <li>○ change in routine</li> <li>○ medication overuse</li> <li>○ social isolation</li> <li>○ changes in sleep hygiene</li> <li>○ poor hydration and/or nutrition</li> </ul> </li> </ul> |
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|   | <ul style="list-style-type: none"> <li>○ lack of aerobic exercise</li> </ul> <p><b>Mental health/ behavioral health sequelae</b></p> <ul style="list-style-type: none"> <li>▪ Conservative approach (ie, minimal diagnostic evaluation, optimizing function and working toward achievable healthy goals) can be considered for the 4 to 12 weeks following illness because potential harm may arise from excessive testing.</li> <li>▪ If concerns persist past 12 weeks (3 months), then additional diagnostic testing (<i>see CDC Interim Guidance on Post-COVID Conditions</i>) and/or referral to a multidisciplinary post-COVID-19 clinic for consultation may be appropriate.</li> </ul>  |
| <b>Management and treatment</b>   |   |
| <p><b>Recommendations for treatment and or management of long COVID</b></p> | <p><b>Neurodevelopmental symptom management</b></p> <ul style="list-style-type: none"> <li>▪ Persistent signs or symptoms require referral to either a neurodevelopmental neurologist, developmental and behavioral pediatrician, neuropsychologist, speech language pathologist, psychologist, and/or physical or occupational therapists.</li> </ul> <p><b>Physical Fatigue/Poor Endurance</b></p> <ul style="list-style-type: none"> <li>▪ Encouraging a consistent daily schedule is helpful. An individualized, goal-driven, gradual increase in physical activity, as tolerated, may be beneficial; however, a subset of patients with post-COVID-19 experience significant postexertional exacerbation of their fatigue and other symptoms after a day of activity while they are “feeling good,” resulting in a “push and crash” cycle, which can slow down their overall trajectory of improvement.</li> <li>▪ Traditional reconditioning protocols can be detrimental and mentally and emotionally aggravating for this population. For these patients, a return to physical activity should be closely monitored by a pediatrician or physical therapist with specialized training or knowledge of postexertional malaise, which differs from a traditional physical therapy reconditioning approach.</li> </ul> <p><b>Headache</b></p> <ul style="list-style-type: none"> <li>▪ Lifestyle factors are typically addressed first; however, if headache symptoms are severe enough to impede recovery, preventive medication may need to be initiated.</li> </ul> <p><b>For individuals with existing mental/behavioral illness</b></p> <ul style="list-style-type: none"> <li>▪ Events surrounding COVID-19 (hospitalisation, isolation, absence from school activities) may exacerbate symptoms.</li> <li>▪ A team-based approach is recommended for those with significant physical impairments or with multiple comorbidities. This team-based approach should be coordinated by the primary care pediatrician, incorporating medical, surgical, occupational, and behavioral specialists as needed.</li> </ul> |
| <b>Service planning</b>   |   |
| <p><b>Recommendations for service planning for long COVID</b></p>           | <p>N/R</p>  |

**Key:** CDC - Centres for Disease Control; N/R – not reported; PASC – post acute sequelae of SARS-CoV-2.

### Appendix 3.8 Data extraction table for Approach to assessment and management of long-term COVID-19 symptoms in primary care

| Clinical guideline and or model of care characteristics  |   |
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| <b>Endorsing Organisation</b>  | British Columbia Ministry of Health   |
| <b>Title</b>   | Approach to assessment and management of long-term COVID-19 symptoms in primary care  |
| <b>Country</b>   | Canada  |
| <b>Date Published</b>  | 5 August 2021   |
| <b>URL</b>   | <a href="http://www.bccdc.ca/Health-Professionals-Site/Documents/Long-term_COVID-19_symptoms_primary_care.pdf">http://www.bccdc.ca/Health-Professionals-Site/Documents/Long-term_COVID-19_symptoms_primary_care.pdf</a>   |
| <b>National or regional</b>  | Regional  |
| <b>Adapted from previous guidelines and or model of care?<br/>If so which guidelines and or model of care was it adapted from?</b> | It is adapted from the <i>NICE Rapid Guideline: Managing the long-term effects of COVID-19</i> and the US Center for Disease Control's Interim Guidance: <i>Evaluating and Caring for Patients with Post-COVID Conditions</i> , supplemented with targeted literature review and expert clinical opinion of the B.C. clinical reference group (CRG).  |
| <b>Update(s) planned (including dates)</b>   | N/R   |
| Definition and diagnosis   |   |
| <b>Definition of long COVID used in the guideline and or model of care</b>   | <p><b>Post-COVID-19 syndrome</b></p> <ul style="list-style-type: none"> <li>▪ Signs and symptoms that develop during or after an infection consistent with COVID-19, continue for more than 12 weeks and are not explained by an alternative diagnosis.</li> </ul> <p><b>PACS</b></p> <ul style="list-style-type: none"> <li>▪ A syndrome characterised by persistent symptoms and/or delayed or long-term complications beyond 4 weeks from the onset of symptoms.</li> </ul> <p><b>PASC</b></p> <ul style="list-style-type: none"> <li>▪ A collective term for the constellation of symptoms some patients experience after recovery from the initial stages of COVID-19 illness.<sup>4</sup> This term is still being defined.</li> </ul> <p><b>Long COVID</b></p> <ul style="list-style-type: none"> <li>▪ Commonly used to describe signs and symptoms that continue or develop after acute COVID-19. It includes both ongoing symptomatic COVID-19 (4-12 weeks) and post-COVID-19 syndrome (defined above).</li> </ul> <p><b>Long-hauler</b></p> <ul style="list-style-type: none"> <li>▪ Some people experiencing long-term symptoms of COVID-19 may self-identify as "long-haulers."</li> </ul> |
| <b>Recommendations for diagnosis of long COVID</b>   | <p><b>Most common signs and symptoms associated with post-COVID-19 recovery</b></p> <ul style="list-style-type: none"> <li>▪ <b>Generalized</b> <ul style="list-style-type: none"> <li>○ persistent fatigue interfering with daily life</li> </ul> </li> </ul>  |



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|  | <ul style="list-style-type: none"> <li>○ post-exertional malaise and/or poor endurance</li> <li>○ fever</li> <li>○ pain</li> <li>○ impaired daily function and mobility</li> <li>▪ <b>Respiratory</b> <ul style="list-style-type: none"> <li>○ cough</li> <li>○ dyspnea or increased respiratory effort</li> </ul> </li> <li>▪ <b>Cardiovascular</b> <ul style="list-style-type: none"> <li>○ chest tightness or pain</li> <li>○ palpitations and/or tachycardia</li> </ul> </li> <li>▪ <b>Gastrointestinal</b> <ul style="list-style-type: none"> <li>○ abdominal pain</li> <li>○ diarrhea</li> <li>○ nausea</li> <li>○ reduced appetite</li> </ul> </li> <li>▪ <b>Dermatological</b> <ul style="list-style-type: none"> <li>○ rash</li> <li>○ hair loss</li> </ul> </li> <li>▪ <b>Neurological</b> <ul style="list-style-type: none"> <li>○ headaches</li> <li>○ sleep problems</li> <li>○ difficulty with problem-solving or cognitive impairment</li> <li>○ paresthesia</li> </ul> </li> <li>▪ <b>Reproductive</b> <ul style="list-style-type: none"> <li>○ menstrual cycle irregularities.</li> </ul> </li> <li>▪ <b>Psychiatric</b> <ul style="list-style-type: none"> <li>○ mood changes (depression, anxiety symptoms).</li> </ul> </li> <li>▪ <b>Musculoskeletal</b> <ul style="list-style-type: none"> <li>○ arthralgia</li> <li>○ myalgia</li> </ul> </li> <li>▪ <b>Ear, nose and throat</b> <ul style="list-style-type: none"> <li>○ sore throat</li> <li>○ dizziness</li> <li>○ loss of sense of smell or taste</li> </ul> </li> </ul> <p><b>Assessment</b></p> <ul style="list-style-type: none"> <li>▪ Take a complete assessment of past medical and social history.</li> </ul> |
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|   | <ul style="list-style-type: none"> <li>▪ Assess severity using a stepwise approach.</li> <li>▪ First rule out red flags (clinical risk factors).</li> <li>▪ Then consider and address yellow flags (psychosocial risk factors that can indicate likelihood of delayed recovery) and need for medical support with returning to work.</li> <li>▪ Red Flag:             <ul style="list-style-type: none"> <li>○ escalating chest pain</li> <li>○ shortness of breath</li> <li>○ unilateral leg swelling</li> <li>○ change in exercise tolerance</li> <li>○ marked change in mental function</li> <li>○ neurologic findings</li> <li>○ atypical severe headache</li> <li>○ deterioration in renal function</li> <li>○ severe psychiatric symptoms including risk of self-harm or suicide</li> </ul> </li> <li>▪ Yellow flags include:             <ul style="list-style-type: none"> <li>○ fear and avoidance of activity</li> <li>○ fear and withdrawal from social interaction</li> <li>○ not participating in self-management (e.g., taking a passive approach to the problem)</li> <li>○ negative attitudes and beliefs about the problem (e.g., that the symptoms are harmful and severely disabling)</li> <li>○ work-related stress</li> </ul> </li> </ul> |
| <b>Management and treatment</b>   |  |
| <p><b>Recommendations for treatment and or management of long COVID</b></p> | <p><b>Management</b></p> <ul style="list-style-type: none"> <li>▪ Educate patients about the typical recovery trajectory and range of experiences (variable symptoms and timeframe).</li> <li>▪ Validate patients’ concerns and provide reassurance.</li> <li>▪ Address symptoms:             <ul style="list-style-type: none"> <li>○ assess and address impact on the patient’s function.</li> <li>○ assess and address impact on the patient’s mental health.</li> <li>○ incorporate the patient’s and family’s cultural and social context into your recommendations.</li> </ul> </li> <li>▪ Ensure COVID-19 diagnosis is documented in the patient’s past medical history for future reference.</li> </ul>  |
| <b>Service planning</b>   |  |
| <p><b>Recommendations for service planning for long COVID</b></p>           | <ul style="list-style-type: none"> <li>▪ Many post-COVID symptoms can be managed by primary care providers, with the incorporation of patient- and family-centered approaches to optimize quality of life and function.</li> </ul>   |

Key: N/R – not reported; PACS - post acute COVID syndrome; PASC - post acute sequelae of SARS-CoV-2.

**Appendix 3.9 Data extraction table for Post COVID-19 Condition: Guidance for Primary Care**

| <b>Clinical guideline and or model of care characteristics</b>   |  |
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| <b>Endorsing Organisation</b>  | Ontario Health, Government of Ontario  |
| <b>Title</b>   | Post COVID-19 Condition: Guidance for Primary Care   |
| <b>Country</b>   | Canada   |
| <b>Date Published</b>  | 14 September 2021  |
| <b>URL</b>   | <a href="https://www.ontariohealth.ca/sites/ontariohealth/files/2021-12/PostCovidConditionsClinicalGuidance_EN.pdf">https://www.ontariohealth.ca/sites/ontariohealth/files/2021-12/PostCovidConditionsClinicalGuidance_EN.pdf</a>  |
| <b>National or regional</b>  | Regional   |
| <b>Adapted from previous guidelines and or model of care?<br/>If so which guidelines and or model of care was it adapted from?</b> | Adapted from Centers for Disease Control and Prevention Interim Guidance (27 September 2021).  |
| <b>Update(s) planned (including dates)</b>   | N/R  |
| <b>Definition and diagnosis</b>  |  |
| <b>Definition of long COVID used in the guideline and or model of care</b>   | <p><b>Narrative text provides a definition</b></p> <ul style="list-style-type: none"> <li>The post-COVID-19 condition (or long COVID) describes a range of symptoms that can persist for months after severe, mildly symptomatic, or asymptomatic SARS-CoV-2 infection. Reference to <a href="https://doi.org/10.47326/ocsat.2021.02.44.1.0">https://doi.org/10.47326/ocsat.2021.02.44.1.0</a></li> </ul> <p><b>Infographic provides this definition</b></p> <ul style="list-style-type: none"> <li>Persons with symptoms <math>\geq 4</math> weeks</li> </ul> |
| <b>Recommendations for diagnosis of long COVID</b>   | <p><b>Common symptoms of post COVID-19</b></p> <ul style="list-style-type: none"> <li>Dyspnea or increased respiratory effort</li> <li>Fatigue</li> <li>Post-exertional malaise and/or poor endurance</li> <li>“Brain fog,” cognitive impairment</li> <li>Cough</li> <li>Chest tightness or pain</li> <li>Headache</li> <li>Palpitations and/or tachycardia</li> <li>Joint pain and stiffness</li> <li>Muscle pain</li> <li>Paresthesia (“pins and needles,” numbness)</li> </ul>  |

- Abdominal pain
- Diarrhea
- Insomnia and other sleep difficulties
- Fever
- Dizziness
- Impaired daily function and mobility
- Pain
- Skin rashes
- Loss of taste and/or smell
- Menstrual cycle irregularities
- Anxiety
- Depression

**Consider a broad range of possible post-COVID-19 conditions**

These could be present prior to a COVID-19 diagnosis and be unmasked by the disease or caused more directly by SARS-CoV-2 infection.

- Cardiovascular:
  - myocarditis
  - heart failure
  - pericarditis
  - orthostatic intolerance (e.g., postural orthostatic tachycardia syndrome)
- Pulmonary:
  - interstitial lung disease
  - reactive airway disease
- Renal:
  - chronic kidney disease
- Dermatologic:
  - alopecia
- Rheumatologic:
  - reactive arthritis
  - fibromyalgia
  - connective tissue disease
- Endocrine:
  - diabetes mellitus
  - hypothyroidism
- Neurologic:

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|  | <ul style="list-style-type: none"> <li>○ transient ischemic attack or stroke</li> <li>○ olfactory and gustatory dysfunction</li> <li>○ sleep dysregulation</li> <li>○ altered cognition</li> <li>○ memory impairment</li> <li>○ headache</li> <li>○ weakness</li> <li>○ neuropathy</li> <li>■ Psychiatric:             <ul style="list-style-type: none"> <li>○ depression</li> <li>○ anxiety</li> <li>○ post-traumatic stress disorder</li> <li>○ psychosis</li> </ul> </li> <li>■ Hematologic:             <ul style="list-style-type: none"> <li>○ pulmonary embolism</li> <li>○ arterial thrombosis</li> <li>○ venous thromboembolism</li> <li>○ other hypercoagulability</li> </ul> </li> <li>■ Urologic:             <ul style="list-style-type: none"> <li>○ incontinence</li> <li>○ sexual dysfunction</li> </ul> </li> </ul> <p><b>Physical Examination and Vital Signs</b></p> <ul style="list-style-type: none"> <li>■ Because multiple organ systems may be involved, a thorough physical examination should be completed</li> <li>■ Standard vital signs:             <ul style="list-style-type: none"> <li>○ blood pressure</li> <li>○ heart rate</li> <li>○ respiratory rate</li> <li>○ pulse oximetry</li> <li>○ body temperature</li> <li>○ body mass index</li> </ul> </li> <li>■ Ambulatory pulse oximetry for people with respiratory symptoms, fatigue, or malaise</li> <li>■ Orthostatic vital signs for people with postural symptoms, dizziness, fatigue, cognitive impairment, or malaise.</li> </ul> <p><b>Assessment and Testing</b></p> <ul style="list-style-type: none"> <li>■ Avoid over-investigation: consider a conservative diagnostic approach in the first 4 to 12 weeks following SARS-CoV-2 infection.</li> </ul> |
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|   | <ul style="list-style-type: none"> <li>▪ Currently, no laboratory test can definitively distinguish the post-COVID-19 condition from other conditions. Any laboratory tests offered should be based on a patient history, physical examination, and clinical findings. For most people, symptom management and a comprehensive rehabilitation plan can be started at the same time as laboratory tests.</li> <li>▪ Tailor tests to the person's signs and symptoms to understand if they are likely to have been caused by ongoing symptomatic COVID-19, the post-COVID-19 condition, or a new unrelated diagnosis.</li> <li>▪ Conduct a chest x-ray by 12 weeks after diagnosis of acute COVID-19 if the person has not already had one and they have continuing respiratory symptoms. The results of a chest x-ray alone should not determine the need for referral for further care.</li> <li>▪ Consider more specialised diagnostic testing for persistent or new respiratory or cardiac concerns in consultation with specialists.</li> </ul>   |
| <b>Management and treatment</b>   |  |
| <p><b>Recommendations for treatment and or management of long COVID</b></p> | <p><b>Supported Self-Management</b></p> <ul style="list-style-type: none"> <li>▪ Advise the person that post-COVID-19 conditions are not yet well understood and that support will continue to be provided as new information emerges.</li> <li>▪ Develop a comprehensive management plan based on presenting symptoms, underlying medical and psychiatric conditions, personal and social situations, and realistic treatment goals.</li> <li>▪ A conservative physical rehabilitation plan might be indicated for some people with post-exertional malaise; cautious initiation of exercise and recommendations about pacing may be useful. If there is a risk of falls, advise the person not to exercise alone.</li> <li>▪ Patient diaries and calendars might be useful for documenting changes in health conditions and symptom severity, and for identifying potential triggers such as exertion (physical and cognitive), foods, menstruation, and treatments or medications.</li> <li>▪ Symptom-management approaches that have been helpful for other conditions such as myalgic encephalomyelitis/chronic fatigue syndrome, fibromyalgia, post-treatment Lyme disease syndrome, dysautonomia, and mast cell activation syndrome may also benefit some people with the post-COVID-19 condition.</li> <li>▪ Provide referrals or information about how to access support from other services, including home care, housing, employment, and financial support.</li> <li>▪ Provide health-promotion education and support (nutrition including vitamin D and B12 intake, physical activity, sleep, stress, chronic disease management).</li> <li>▪ Consider referral to a relevant specialist or interprofessional rehabilitation team on the initial visit if symptoms are moderate to severe or worsening.</li> </ul> <p><b>Medications</b></p> <ul style="list-style-type: none"> <li>▪ Treat fever as needed; acetaminophen is preferable to NSAIDs because of their cardiovascular risks.</li> <li>▪ Medications may be helpful for indicated symptoms or illnesses (e.g., headache or anxiety).</li> </ul> |

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|  | <ul style="list-style-type: none"> <li>▪ Ask about people’s use of supplements, herbal remedies, or other treatments.</li> </ul> <p><b>Mental Health Supports</b></p> <ul style="list-style-type: none"> <li>▪ Refer to community mental health services as appropriate.</li> <li>▪ Consider the mental health needs of caregivers as well.</li> </ul> <p><b>Referral to Interprofessional Rehabilitation Teams</b></p> <ul style="list-style-type: none"> <li>▪ Any time from 4 weeks after the onset of acute COVID-19 illness.</li> <li>▪ A list of post-COVID-19 condition rehabilitation programs in Ontario can be found here.</li> <li>▪ The PCFS can be used to guide referral to interprofessional rehabilitation programs for the post-COVID-19 condition:             <ul style="list-style-type: none"> <li>○ a PCFS score of 3 or 4</li> <li>○ a PCFS score of 2, but with symptoms persisting 8 weeks or more after SARS-CoV-2 infection</li> </ul> </li> </ul> |
| <b>Service planning</b>                                    |   |
| <b>Recommendations for service planning for long COVID</b> | N/R   |

**Key:** N/R - not reported; PCFS - post-COVID-19 functional status scale; post exertional malaise is the worsening of symptoms following even minor physical or mental exertion, with symptoms typically worsening 12 to 48 hours after activity and lasting for days or even weeks.

### Appendix 3.10 Data extraction table for Recommendations for the recognition, diagnosis, and management of long COVID: a Delphi study

| Clinical guideline and or model of care characteristics  |  |
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| <b>Endorsing Organisation</b>  | No official endorsing organisation: UK panel of primary and secondary care doctors   |
| <b>Title</b>   | Recommendations for the recognition, diagnosis, and management of long COVID: a Delphi study   |
| <b>Country</b>   | UK   |
| <b>Date Published</b>  | 28 October 2021  |
| <b>URL</b>   | <a href="https://doi.org/10.3399/BJGP.2021.0265">https://doi.org/10.3399/BJGP.2021.0265</a>  |
| <b>National or regional</b>  | Regional   |
| <b>Adapted from previous guidelines and or model of care?<br/>If so which guidelines and or model of care was it adapted from?</b> | N/A  |
| <b>Update(s) planned (including dates)</b>   | N/R  |
| Definition and diagnosis   |  |
| <b>Definition of long COVID used in the guideline and or model of care</b>   | <p><b>Long COVID</b></p> <ul style="list-style-type: none"> <li>▪ Prolonged symptoms at <math>\geq 4</math> weeks.</li> </ul>  |
| <b>Recommendations for diagnosis of long COVID</b>   | <p><b>Recommendations relating to diagnosis of underlying disorders</b></p> <p><b>General approach</b></p> <ul style="list-style-type: none"> <li>▪ In someone with long COVID, symptoms of possible non-COVID-19-related issues should be investigated and referred as per local guidelines. Long COVID alone is not a sufficient diagnosis unless other causes have been excluded.</li> <li>▪ Carry out a face-to-face assessment including a thorough history and examination, consider other non-COVID-19-related diagnoses, and measure full blood count, renal function, C-reactive protein, liver function test, thyroid function, haemoglobin A1c, vitamin D, magnesium, a B12, folate, ferritin, and bone studies. (aMagnesium level may not be available in general practice)</li> </ul> <p><b>Respiratory</b></p> <ul style="list-style-type: none"> <li>▪ In those with respiratory symptoms, consider chest X-ray at an early stage. Be aware that a normal appearance does not exclude respiratory pathology.</li> </ul> |



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|   | <ul style="list-style-type: none"> <li>▪ Be aware that simple spirometry may be normal but patients may have diffusion defects indicative of scarring, chronic pulmonary embolisms, or microthrombi. Consider referral to respiratory for full lung function testing.</li> <li>▪ Measure oxygen saturation at rest and after an age-appropriate brief exercise test in people with breathlessness and refer for investigation if hypoxaemic or if any desaturation on exercise.</li> </ul> <p><b>Cardiac</b></p> <ul style="list-style-type: none"> <li>▪ Consider the possibility of a cardiac cause of breathlessness.</li> <li>▪ Be aware that a normal D-dimer may not exclude thromboembolism, especially in a chronic setting, and referral for investigation is therefore indicated if there is a clinical suspicion of pulmonary emboli. Additionally, be mindful that thromboembolism may occur at any stage during the disease course.</li> <li>▪ In patients with inappropriate tachycardia and/or chest pain, carry out electrocardiogram, troponin, Holter monitoring, and echocardiography. Be aware that myocarditis and pericarditis cannot be excluded on echocardiography alone.</li> <li>▪ In patients with chest pain, consider a referral to cardiology as cardiac magnetic resonance imaging may be indicated in a normal echo to rule out myopericarditis and microvascular angina.</li> <li>▪ In patients with palpitations and/or tachycardia, consider autonomic dysfunction</li> </ul> <p><b>Others</b></p> <ul style="list-style-type: none"> <li>▪ In patients with urticaria, conjunctivitis, wheeze, inappropriate tachycardia, palpitations, shortness of breath, heartburn, abdominal cramps or bloating, diarrhoea, sleep disturbance, or neurocognitive fatigue, consider mast cell disorder.</li> <li>▪ In patients with cognitive difficulties sufficient to interfere with work or social functioning, consider neurocognitive assessment.</li> <li>▪ In patients with joint swelling and arthralgia, consider a diagnosis of reactive arthritis or new connective tissue disease and investigate and refer as appropriate.</li> </ul> |
| <b>Management and treatment</b>   |  |
| <p><b>Recommendations for treatment and or management of long COVID</b></p> | <p><b>Recommendations relating to management: general approach</b></p> <ul style="list-style-type: none"> <li>▪ For patients with fatigue and worsening symptoms hours to days following an activity, emphasise the importance of an initial phase of convalescence followed by careful pacing and rest.</li> <li>▪ Support patients in shifting their mental timeline of recovery to reflect the likely prolonged course, with a possibly long phased return to work.</li> <li>▪ Further support patients with signposting to patient resources. Applicable resources may include: management of post-exertional symptom exacerbation, activity pacing, acupuncture, diagnosis-specific management as relevant.</li> <li>▪ Provide patients with signposting to social prescribing, sickness certification, and financial advice. Discuss with the patient whether sickness certification will state long COVID as diagnosis.</li> </ul>  |

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|   | <ul style="list-style-type: none"> <li>▪ Clinicians should ensure that the occupational status of patients with long COVID is recorded (in/out of work, part-/full-time, student).</li> <li>▪ Follow patients up regularly to monitor progress from a full biopsychosocial and occupational perspective.</li> <li>▪ Encourage reporting of new symptoms (expected) and expectation of waxing–waning course.</li> <li>▪ Consider contributing patient data to research on long COVID, using the WHO Case Report Form or similar.</li> </ul> <p><b>Recommendations relating to management: specific conditions</b></p> <ul style="list-style-type: none"> <li>▪ Patients with cardiac symptoms should be advised to limit their heart rate to 60% of maximum (usually around 100–110 beats per minute) and investigated with at least electrocardiogram and echocardiogram before taking up exercise. Supervised exercise testing should be considered for this patient group as they may have perimyocarditis and exercise carries risk of arrhythmia and worsening cardiac function.</li> <li>▪ For autonomic dysfunction including PoTs, consider first increased fluids, salts, compression hosiery, and specific rehabilitation.</li> <li>▪ If PoTS and no or inadequate response to non-pharmacological therapy consider beta-blocker, ivabradine, or fludrocortisone (with blood pressure and response monitoring).</li> <li>▪ In patients with possible mast cell disorder, consider a 1-month trial of initial medical treatment and dietary advice. Higher than standard dose of antihistamines are commonly used for this indication. If partial effect, consider adding second-level treatment such as montelukast, as well as referral to allergy or immunology specialists.</li> <li>▪ Be aware that adverse drug reactions are more common in patients with mast cell disorder, e.g., to beta-lactam antibiotics, non-steroidal anti-inflammatory drugs, codeine, morphine, or buprenorphine.</li> <li>▪ For breathing pattern disorder, consider specialist physiotherapy and or using alternative therapies such as pranayama breathing and meditation.</li> <li>▪ In patients expressing distress, significant low mood, anxiety, or symptoms of post-traumatic stress disorder, consider mental health assessment.</li> <li>▪ Over-the-counter supplementation is common, including vitamin C, D, niacin (nicotinic acid), and quercetin. Be aware of significant drug interactions, such as with niacin or quercetin.</li> </ul> |
| <b>Service planning</b>   |  |
| <p><b>Recommendations for service planning for long COVID</b></p> | <p><b>Recommendations relating to clinic organisation</b></p> <ul style="list-style-type: none"> <li>▪ Consider long COVID in patients with a clinical diagnosis of COVID-19 as per WHO criteria or test-positive history with new or fluctuating symptoms including but not limited to breathlessness, chest pain, palpitations, inappropriate tachycardia, wheeze, stridor, urticaria, abdominal pain, diarrhoea, arthralgia, neuralgia, dysphonia, fatigue including neurocognitive fatigue, cognitive impairment, prolonged pyrexia, and neuropathy occurring beyond 4 weeks of initial COVID-19.</li> <li>▪ Multi-specialty long COVID clinics should be led by a doctor with cross-specialty knowledge and experience of managing this condition.</li> </ul>   |

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|  | <ul style="list-style-type: none"><li>▪ Consider individualised investigations, management, and rehabilitation planning via a multi-specialty long COVID assessment service as local services allow. Prioritise physician-led medical assessments and diagnostics initially, and consider allied health professionals including physiotherapy and occupational therapist input as adjuncts.</li><li>▪ It is inappropriate for long COVID clinics to be led by mental health specialists, e.g., Improved Access to Psychological Therapy, clinical or health psychologist. They may be useful in supporting the multi-specialty team but do not have the expertise to investigate and manage potential organ damage.</li><li>▪ All under-18-year-olds need access to similar services run by paediatric specialists with knowledge of how presentations and treatments differ for adults and with close liaison with school.</li><li>▪ Patients with comorbid mental health difficulties should have equal access to medical care as a patient without mental health difficulties and should not be triaged away from services.</li></ul> |
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**Key:** N/A - not applicable; N/R – not reported; PoTs - postural orthostatic tachycardia syndrome.

### Appendix 3.11 Data extraction table for Management of post-acute COVID-19 patients in geriatric rehabilitation: EuGMS guidance

| Clinical guideline and or model of care characteristics  |  |
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| <b>Endorsing Organisation</b>  | European Geriatric Medicine Society  |
| <b>Title</b>   | Management of post-acute COVID-19 patients in geriatric rehabilitation: EuGMS guidance   |
| <b>Country</b>   | Europe   |
| <b>Date Published</b>  | 20 November 2021   |
| <b>URL</b>   | <a href="https://doi.org/10.1002/pmrj.12684">https://doi.org/10.1002/pmrj.12684</a>  |
| <b>National or regional</b>  | Applicable for the European context - International  |
| <b>Adapted from previous guidelines and or model of care?<br/>If so which guidelines and or model of care was it adapted from?</b> | Adapted from the Dutch Association of Elderly Care Physicians and Social Geriatricians (not available in English) ( <a href="#">link</a> and <a href="#">link</a> ).   |
| <b>Update(s) planned (including dates)</b>   | Stated to be regularly updated based on additional evidence from practice and research.  |
| Definition and diagnosis   |  |
| <b>Definition of long COVID used in the guideline and or model of care</b>   | <p><b>Post-acute COVID-19</b></p> <ul style="list-style-type: none"> <li>Refers to patients who have survived the acute phase of the disease at home or in a hospital, and are currently recovering.</li> </ul>  |
| <b>Recommendations for diagnosis of long COVID</b>   | <p><b>General</b></p> <ul style="list-style-type: none"> <li>Performing CGA to gain insight in the frailty status, functional prognosis, trainability, cognition and motivation of the patient (or use data from recently performed CGA).</li> <li>Anamnesis: somatic, functional, psychological, existential and social domain.</li> <li>Performing measurements and screening on all domains.</li> <li>Reporting on the findings of the CGA in the (electronic) patient file.</li> <li>Formulating treatment goals with the patient and his/her relatives, resulting in a treatment plan (by applying shared decision-making).</li> <li>Discussing policy with patient and his/her family (if applicable) in case of deterioration (advance care planning, non-COVID-19-related).</li> <li>Starting the discharge-process as soon as possible.</li> <li>Discussing expected duration of rehabilitation treatment (expected week of discharge).</li> <li>Discussing expected discharge location (home, residential care setting, nursing home).</li> </ul> <p><b>COVID-19</b></p> |

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|   | <ul style="list-style-type: none"> <li>▪ Specific focus in all domains of CGA on COVID-19-related complications and symptoms.</li> <li>▪ Due to contact restrictions/lockdowns it is important to make a structured caregiver communication plan, in which consultations with care professionals are planned in advance, to guide the informal caregivers through the rehabilitation process and to provide them the opportunity to ask questions (e.g. at admission, in-between (frequency depends on the expected length of stay), and prior to discharge). Understanding the shielding requirements of caregivers is important as many will be vulnerable to COVID-19.</li> <li>▪ Discussing the relevant COVID-19 policies with patient and family (if applicable) with regard to testing, visiting, safety measures, quarantine, use of protective measures, vaccination and hygiene.</li> <li>▪ Discussing policy with patient and their family (if applicable) in case of deterioration (advance care planning, COVID-19-related).</li> </ul>  |
| <b>Management and treatment</b>   |   |
| <p><b>Recommendations for treatment and or management of long COVID</b></p> | <p><b>Post-acute COVID-19 patients admitted after hospitalisation</b></p> <ul style="list-style-type: none"> <li>▪ Patients can be admitted to geriatric rehabilitation after discharge from hospital either following an ICU admission or ward-based care. COVID-19 patients discharged from hospital after ICU admission can be affected by a variety of problems, such as the PICS, including impairments in physical, cognitive, and/or mental functioning. These patients are often severely deconditioned, oxygen-dependent, have limited pulmonary and respiratory reserve, and may have comorbidities which have decompensated during their acute admission. Furthermore, they are often experience psychological problems (such as PTSD) and cognitive problems. They require extra attention towards malnutrition, breathing issues, swallowing impairment and oropharyngeal dysphagia. A focus on prevention of sputum retention, aspiration and pressure ulceration is required.</li> <li>▪ Within the group of COVID-19 patients discharged from hospital without ICU admission, 2 subgroups can be distinguished; <ul style="list-style-type: none"> <li>○ The first subgroup consists of patients with severe sarcopenia, who are severely deconditioned, combined with pre-existing frailty and complex health problems. Initially, these patients are often dependent on additional oxygen and have moderate psychological and cognitive problems.</li> <li>○ The second subgroup consists of older patients who were not substantially frail before COVID-19 infection, but who need an extended period of recovery. This recovery is mainly aimed at becoming independent from oxygen, regaining mobility and improving physical condition. They may be comorbid to some extent, but are not severely impaired by these comorbidities. In general they only have minor or no psychological or cognitive problems.</li> </ul> </li> </ul> <p><b>Post-acute COVID-19 patients admitted from home.</b></p> <ul style="list-style-type: none"> <li>▪ Within the group of COVID-19 patients admitted to geriatric rehabilitation from home, 2 subgroups can be distinguished; <ul style="list-style-type: none"> <li>○ The first group are COVID-19 patients who are independently living or living in a residential care setting. Due to COVID-19 they have a relatively high care dependency, which makes the care</li> </ul> </li> </ul> |

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|  | <p>burden for their caregivers too high. Hospital admission is considered not necessary or appropriate for this group because they do not need additional oxygen, or oxygen is already being administered at home. Patients in this group are often very frail and have a high risk of impaired functional outcome and mortality. Their clinical trajectory is hard to predict. Some of these patients will recover, but they may need a relatively long period of recovery and/or rehabilitation; others will not be able to continue living independently (especially in case of a lack of informal support) and are admitted to a residential or long term care facility.</p> <ul style="list-style-type: none"> <li>○ The second subgroup are older patients who were not substantially frail before COVID-19 and who have initially been discharged home after hospitalisation, but who need rehabilitation because they experience substantial problems with their activities of daily living due to COVID-19. This rehabilitation is mainly aimed at improving physical condition and the ability to perform activities of daily living.</li> </ul> <p><b>Treatment goals and actions per domain</b></p> <p><b><i>Somatic domain</i></b></p> <ul style="list-style-type: none"> <li>▪ General <ul style="list-style-type: none"> <li>○ Improve the general condition of the body, stamina and muscle strength, and treatment of sarcopenia (including sufficient attention for the balance between what is possible and what is not possible given current impairments, and for nutrition and exercise).</li> <li>○ Optimizing the somatic part of geriatric syndromes (e.g. incontinence—treatment or urinary tract infection; insomnia—day/night regulation, medication; impaired vision—contact caregiver (glasses); hearing loss—including treatment of cerumen impaction).</li> <li>○ Improving nutritional status (by sufficient food intake and/or attention for increased protein, vitamin and energy intake).</li> </ul> </li> <li>▪ COVID-19 <ul style="list-style-type: none"> <li>○ Medication review and optimising medication use (including attention to anticholinergic burden for those with cognitive impairment).</li> <li>○ Regulating and/or dismantling the use of oxygen.</li> <li>○ Managing cannula care or post-cannula problems, proper management of IV lines or PICC lines.</li> <li>○ Stabilise and/or treat comorbidity (e.g. hypertension, pain (peripheral neuropathic pain post ICU)).</li> <li>○ Preventing functional loss due to complications (e.g. preventing contractures, prevent and treat pulmonary complications and pressure ulcers).</li> <li>○ Managing and/or improving functional swallowing capacity (e.g. functional speech therapy and clinical nutrition).</li> </ul> </li> </ul> <p><b><i>Functional domain</i></b></p> <ul style="list-style-type: none"> <li>▪ General</li> </ul> |
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|  | <ul style="list-style-type: none"> <li>○ Assisting patients to manage personal activities of daily living without the assistance of another person (i.e. improving self-management skills). If this is not possible, the goal is to minimise the need for external assistance through the use of adaptive techniques and equipment, aiming at the highest achievable level of independence.</li> <li>○ Improving mobility: independent transfers, walking (with or without walking aids), climbing stairs.</li> <li>○ Assessing and adapting the home environment if necessary.</li> <li>■ COVID-19       <ul style="list-style-type: none"> <li>○ Improving swallowing and breathing techniques, speech techniques, breathing power, and coughing techniques (in case of respiratory obstruction).</li> <li>○ Gaining insight in reduced energy levels including learning compensation strategies.</li> </ul> </li> </ul> <p><b>Psychological domain</b></p> <ul style="list-style-type: none"> <li>■ General       <ul style="list-style-type: none"> <li>○ Gaining insight in cognitive changes and learning strategies to compensate for this.</li> </ul> </li> <li>■ COVID-19       <ul style="list-style-type: none"> <li>○ Stabilising mood (timely diagnosis and treatment of depression, fear and PTSD; assessing possible impairing psychological factors).</li> <li>○ Supporting patient and family (if applicable); timely identification of psychological complaints related to PICS-family, and emotional overload.</li> </ul> </li> </ul> <p><b>Existential domain</b></p> <ul style="list-style-type: none"> <li>■ General       <ul style="list-style-type: none"> <li>○ Mapping sources for resilience and supporting resilience.</li> <li>○ Exploring questions regarding identity, values and meaning of life.</li> </ul> </li> <li>■ COVID-19       <ul style="list-style-type: none"> <li>○ Support in processing experiences around suffering and fear of dying.</li> <li>○ Supporting to overcome COVID-19 as a life event.</li> <li>○ Spiritual counselling.</li> </ul> </li> </ul> <p><b>Social domain</b></p> <ul style="list-style-type: none"> <li>■ General       <ul style="list-style-type: none"> <li>○ Improving social participation, based on personal goal setting.</li> <li>○ Mobilising practical and social support.</li> <li>○ Supporting informal caregivers and the patients' social network.</li> </ul> </li> <li>■ COVID-19       <ul style="list-style-type: none"> <li>○ Reintegration into social life within COVID-19-related social restriction measures.</li> </ul> </li> </ul> <p><b>Activities during treatment phase</b></p> <ul style="list-style-type: none"> <li>■ General       <ul style="list-style-type: none"> <li>○ Execution of the treatment plan by the disciplines involved.</li> </ul> </li> </ul> |
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|  | <ul style="list-style-type: none"> <li>○ Continuous monitoring of signs and symptoms and course of recovery.</li> <li>○ Evaluation and adaptation of treatment goals and treatment plan if necessary.</li> <li>○ Actively engaging patient and family/informal caregivers (if applicable) in the evaluation and treatment decisions, and support them in shared decision-making if needed.</li> <li>○ Monitoring and reporting the progress in the (electronic) patient file.</li> <li>■ COVID-19       <ul style="list-style-type: none"> <li>○ Specific focus on monitoring COVID-19-related symptoms, complications and their interaction with other comorbidities, next to regular functional outcome measurement.</li> <li>○ Specific focus on monitoring COVID-19 contagiousness.</li> <li>○ Check vaccination status/indication.</li> </ul> </li> </ul> <p><b>Activities during discharge phase</b></p> <ul style="list-style-type: none"> <li>■ General       <ul style="list-style-type: none"> <li>○ Prepare the patient and their relatives/informal caregivers for discharge and support them in the transition of the patient to the home environment or other care setting.</li> <li>○ Performing measurements and screening on all relevant domains</li> <li>○ Assess whether there is a need for medical aids (including oxygen) in the home.</li> <li>○ Assess whether there is a need for aftercare in the home (such as outpatient rehabilitation, primary care physiotherapy, home care, etc.).</li> <li>○ Discuss the necessary preparations with the patient, family/informal caregivers (if applicable).</li> <li>○ Prepare timely and detailed transfer of patient records to primary care professionals.</li> </ul> </li> <li>■ COVID-19       <ul style="list-style-type: none"> <li>○ Discussing relevant COVID-19 policies with patient and family (if applicable) with regard to safety measures</li> <li>○ Specific focus in measurement and screening on COVID-19-related complications and their interaction with other comorbidities, next to regular functional outcome measurement</li> <li>○ Assess the home environment and social network of the patient, bearing in mind current social distancing policies.</li> </ul> </li> </ul> <p><b>Follow up</b></p> <ul style="list-style-type: none"> <li>■ We recommend to assess at follow-up the availability of informal caregivers, caregiver strain and additional measures if indicated based on the status of the patients at follow-up. Monitoring during follow-up can be performed by the patient's GP (or another member of the primary care team, such as a nurse practitioner). eHealth applications can be used for monitoring purposes. Preferably widely acknowledged measurement instruments should be used for this monitoring. In case of problems in these domains, the patients should be referred to other care professionals if indicated, such as a physiotherapist, occupational therapist, dietician, speech and language therapist, psychologist, social worker, specialised nurse, geriatrician or physician specialised in geriatric rehabilitation.</li> </ul> |
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|   | <ul style="list-style-type: none"> <li>It is recommended to regularly (e.g. on a weekly basis) administer rapid diagnostic tests, e.g. Lateral Flow Tests, during geriatric rehabilitation of post-acute COVID-19 patients, although the positive predictive validity and hence clinical utility of these will vary as background prevalence changes and such policies should be subject to regular review in conjunction with public health experts. Furthermore, it is highly recommended to create an internationally agreed upon and standardised register for COVID-19 patients in geriatric rehabilitation, including a selection of widely used measurement instruments.</li> </ul>   |
| <b>Service planning</b>   |  |
| <p><b>Recommendations for service planning for long COVID</b></p> | <p><b>Geriatric needs assessment</b></p> <ul style="list-style-type: none"> <li>This is preferably conducted by a geriatrician or a physician specialised in geriatric rehabilitation and/or delegates from the wider rehabilitation multidisciplinary team (if necessary in consultation with other disciplines such as a consultant in rehabilitation, lung specialist, internist, etc.).</li> <li>The geriatric assessment should conclude whether the rehabilitation should be provided in a geriatric rehabilitation facility, medical specialist rehabilitation facility or specialised pulmonary rehabilitation facility (if available), and the choice should be tailored by matching the patients' needs to the medical, therapist, and nursing provision available in the receiving facility.</li> <li>Lastly, based on the geriatric needs assessment, a decision for inpatient care, outpatient care or a combination of the 2 should be taken. Outpatient geriatric rehabilitation can be provided at an outpatient clinic or in the home of the patient. The decision for inpatient or outpatient care, also depends on the available services in the member countries, local circumstances, and the availability of informal care for the patient</li> <li>For care facilities with fewer disciplines in the multidisciplinary teams, certain goals may be assigned to other disciplines. Collaboration with disciplines from other care organisations should be organised, if needed to meet the needs of the patients. Within geriatric rehabilitation the interchange between disciplines is very important and the care professionals involved in geriatric rehabilitation should have a flexible and interdisciplinary work approach. Furthermore, it is recommended that the geriatric rehabilitation team collaborates closely with a (clinical) pharmacist given the impact of polypharmacy on rehabilitation and recovery and the changes to drug regimens which are commonly a part of COVID-19 care.</li> <li>It is recommended that the geriatric rehabilitation team collaborates closely with a (clinical) pharmacist given the impact of polypharmacy on rehabilitation and recovery and the changes to drug regimens which are commonly a part of COVID-19 care</li> <li>Facilities providing geriatric rehabilitation to post-acute COVID-19 patients are invited and encouraged to participate in the EU-COGER study or join an international standardised register for COVID-19 patients in geriatric rehabilitation, after the COGER study is completed.</li> </ul> |

**Key:** CGA - comprehensive geriatric assessment; ICU - intensive care unit; IV - intravenous; PICC- peripherally inserted central catheter; PICS – post intensive care syndrome; PTSD - post traumatic stress disorder.

### Appendix 3.12 Data extraction table for ESCMID rapid guidelines for assessment and management of long COVID

| Clinical guideline and or model of care characteristics  |   |
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| <b>Endorsing Organisation</b>  | European Society of Clinical Microbiology and Infectious Diseases (ESCMID)  |
| <b>Title</b>   | ESCMID rapid guidelines for assessment and management of long COVID   |
| <b>Country</b>   | European  |
| <b>Date Published</b>  | 17 February 2022  |
| <b>URL</b>   | <a href="https://doi.org/10.1016/j.cmi.2022.02.018">https://doi.org/10.1016/j.cmi.2022.02.018</a>   |
| <b>National or regional</b>  | International   |
| <b>Adapted from previous guidelines and or model of care?<br/>If so which guidelines and or model of care was it adapted from?</b> | Existing guidelines were used to inform recommendations; <a href="#">NICE</a> , <a href="#">sumsearch</a> , and <a href="#">SIGN</a> ) and other health institutes ( <a href="#">NIH</a> , <a href="#">CDC</a> , and <a href="#">WHO</a> ).   |
| <b>Update(s) planned (including dates)</b>   | Authors plan to modify guidelines with upcoming new evidence. The panel will meet monthly regarding the need for updates. The panel members will perform an updated search every 3 months and will update the guidelines once substantial evidence for changing any recommendation is observed.   |
| Definition and diagnosis   |   |
| <b>Definition of long COVID used in the guideline and or model of care</b>   | <p><b>Post-acute COVID</b></p> <ul style="list-style-type: none"> <li>▪ One or more symptoms and/or signs persisting or relapsing/remitting from 4 to 12 weeks since a confirmed acute COVID-19 diagnosis, without an alternative diagnosis. This definition also includes several specific entities (thyroiditis, myocarditis, venous thromboembolism) that may appear during this period.</li> </ul> <p><b>Long COVID</b></p> <ul style="list-style-type: none"> <li>▪ One or more symptoms and/or signs persisting or relapsing/remitting for more than 12 weeks since an acute COVID-19 diagnosis, without an alternative explanation.</li> </ul> |
| <b>Recommendations for diagnosis of long COVID</b>   | <p><b>Symptoms</b></p> <ul style="list-style-type: none"> <li>▪ General: <ul style="list-style-type: none"> <li>○ fatigue</li> <li>○ fever/feverish</li> <li>○ headache</li> <li>○ chest pain/tightness</li> </ul> </li> <li>▪ Musculoskeletal: <ul style="list-style-type: none"> <li>○ joint pain/arthritis</li> <li>○ myalgia</li> </ul> </li> </ul>   |

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|  | <ul style="list-style-type: none"> <li>▪ Respiratory: <ul style="list-style-type: none"> <li>○ dyspnoea</li> <li>○ exertional dyspnoea</li> <li>○ cough</li> <li>○ sore throat</li> </ul> </li> <li>▪ Gustatory: <ul style="list-style-type: none"> <li>○ ageusia/dysgeusia</li> <li>○ anosmia</li> <li>○ loss of appetite</li> </ul> </li> <li>▪ Neuropsychological: <ul style="list-style-type: none"> <li>○ confusion/brain fog</li> <li>○ depression</li> <li>○ sleep disorders</li> <li>○ post-traumatic stress disorder</li> </ul> </li> <li>▪ Cardiovascular: <ul style="list-style-type: none"> <li>○ palpitations</li> </ul> </li> <li>▪ Skin: <ul style="list-style-type: none"> <li>○ rash</li> </ul> </li> </ul> <p><b>Who should be assessed for long COVID? – Recommendation</b></p> <ul style="list-style-type: none"> <li>▪ As a first step, collecting specific clinical history is recommended to rule out previous underlying conditions, as well as iatrogenic causes or complications related to the acute episode. Hence, any patient with persisting or new symptoms that last more than 12 weeks after acute COVID-19 should be referred to medical care. For patients with symptoms 4 to 12 weeks after acute infection, assessment should be considered on a case-by-case basis, according to the severity and course of symptoms.</li> </ul> <p><b>General Diagnostic Blood Tests – Recommendations (Adapted from other guidelines)</b></p> <ul style="list-style-type: none"> <li>▪ The following may be considered for symptomatic patients according to symptoms: <ul style="list-style-type: none"> <li>○ C-reactive protein, blood count, kidney function, and liver function tests.</li> <li>○ Consider troponin, CPK-MB, and B-type natriuretic peptide for cardiac symptoms and complete thyroid function tests to rule out thyroiditis, if clinically suspected.</li> <li>○ For patients with decreased oxygen saturation, blood gases are recommended by some guidelines, although the benefit of this test is limited.</li> <li>○ D-dimer should not be used in patients without respiratory symptoms.</li> <li>○ Patients at increased risk for diabetes or impaired fasting glucose should be monitored for fasting glucose and glycated haemoglobin levels.</li> </ul> </li> </ul> <p><b>Dyspnea Diagnostic Tests</b><br/> <b><i>Pulmonary function testing – Recommendation</i></b></p> |
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|  | <ul style="list-style-type: none"> <li>▪ Evidence is insufficient to provide a recommendation for or against PFT. Considering that the test is simple and noninvasive and that future studies may suggest beneficial treatment for patients with abnormal PFT, the panel recommends considering routine PFT, including diffusion capacity, in all patients with severe and critical COVID-19 at 3 months from diagnosis, regardless of symptoms, as well as considering completing PFT with diffusion for patients reporting persistent dyspnoea 3 months after acute disease and those with known prior lung disease.</li> </ul> <p><b>Chest X-ray – Recommendation</b></p> <ul style="list-style-type: none"> <li>▪ Evidence is insufficient to provide a recommendation for or against chest x-ray. Chest x-ray may be considered in patients with long COVID and persistent respiratory symptoms at 3 months to rule out other diagnoses and for a possible early diagnosis of pulmonary fibrosis.</li> </ul> <p><b>Chest CT/MRI – Recommendations</b></p> <ul style="list-style-type: none"> <li>▪ Evidence is insufficient to provide a recommendation for or against chest imaging. Chest CT should be considered at 3 to 6 months in patients with dyspnoea or abnormal PFTs, regardless of symptoms, to rule out other causes and identify fibrotic changes.</li> </ul> <p><b>Dyspnoea, Cardiac Complaints, and Fatigue Diagnostic Tests</b></p> <p><b>Cardiac imaging – Recommendations</b></p> <ul style="list-style-type: none"> <li>▪ Evidence is insufficient to provide recommendations for or against any of the aforementioned cardiac tests. Considering TTE is noninvasive, it may be offered for patients presenting with persistent symptoms suggestive of perimyocardial injury (chest pain, palpitations, signs and symptoms of heart failure). It is reasonable that for patients who had cardiac abnormalities during acute disease (myocarditis, pericarditis, heart failure), a repeat TTE would be performed at 2 to 3 months. Further investigation for cardiac abnormalities should be performed according to symptoms in patients presenting with cardiac symptoms. Cardiac MRI should only be performed on a case-by-case basis with a specific clinical question in mind (e.g. athletes returning to physical activity).</li> </ul> <p><b>Functional testing – Recommendations</b></p> <ul style="list-style-type: none"> <li>▪ Evidence is insufficient to provide recommendations for or against functional tests (6-minute-walk test, sit-to stand test, Short Physical Performance Battery, Cardiopulmonary stress test). Consider performing them at the beginning of an interventional/rehabilitation program to assess progress.</li> </ul> <p><b>Neurocognitive Complaints Diagnostic Tests</b></p> <p><b>Brain imaging – Recommendations</b></p> <ul style="list-style-type: none"> <li>▪ Limited evidence does not support the use of brain imaging to investigate long-COVID complaints, other than to rule out other causes or for research purposes.</li> </ul> |
| <b>Management and treatment</b>                                      |   |
| <b>Recommendations for treatment and or management of long COVID</b> | <b>Recommendations for management of patients with long COVID</b><br><i>Thromboprophylaxis</i>  |

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|  | <ul style="list-style-type: none"> <li>▪ Evidence is insufficient to provide a recommendation for or against the intervention. It is advisable to perform individualised risk stratification of the risk for thrombotic events vs. haemorrhagic events. Consider extended anticoagulation prophylaxis for patients with a low risk of bleeding and elevated risk for VTE (active malignancy, immobility, history of VTE, recent major surgery, thrombophilia).</li> </ul> <p><b><i>Pulmonary Rehabilitation</i></b></p> <ul style="list-style-type: none"> <li>▪ Evidence is insufficient to provide a recommendation for or against pulmonary rehabilitation specifically for COVID-19. No data regarding persistent long COVID were identified. Until further evidence accumulates, it is reasonable that clinicians follow available consensus statements regarding multidisciplinary rehabilitation in the post-acute stage.</li> </ul> <p><b><i>Management of Persistent Pulmonary Symptoms</i></b></p> <ul style="list-style-type: none"> <li>▪ Evidence is insufficient to provide a recommendation for or against any intervention (e.g. corticosteroids, antifibrotic agents).</li> </ul> <p><b><i>Management of Persistent Cough</i></b></p> <ul style="list-style-type: none"> <li>▪ Evidence is insufficient to provide a recommendation for or against any intervention (e.g. gabapentin, pregabalin, antimuscarinic drugs)</li> </ul> <p><b><i>Management of Smell and Taste Disturbances</i></b></p> <ul style="list-style-type: none"> <li>▪ Evidence is insufficient to provide a recommendation for or against any intervention. Due to its simplicity and safety, olfactory training should probably be suggested for all patients. Physicians should discuss the likelihood for spontaneous recovery with patients, and other interventions should be suggested only in clinical trials.</li> <li>▪ Smoking cessation should be recommended.</li> </ul> <p><b><i>Management of Fatigue</i></b></p> <ul style="list-style-type: none"> <li>▪ Evidence is insufficient to provide a recommendation for or against any intervention (e.g. medications, complementary and alternative medicine, cognitive behavioural therapy, and exercise)</li> </ul> <p><b><i>Management of Neurological/Cognitive long COVID Sequelae</i></b></p> <ul style="list-style-type: none"> <li>▪ Evidence is insufficient to provide a recommendation for or against any intervention (e.g. pharmacological).</li> </ul> <p><b><i>Management of Emotional/Psychiatric long COVID Sequelae</i></b></p> <ul style="list-style-type: none"> <li>▪ Evidence is insufficient to provide a recommendation for or against any intervention (e.g. pharmacological).</li> </ul> |
| <b>Service planning</b>                                    |  |
| <b>Recommendations for service planning for long COVID</b> | N/R  |

**Key:** CDC - Centres for Disease Control and Prevention; CPK-MB - creatine phosphokinase myocardial band; CT - computed tomography; ESCMID - European Society of Clinical Microbiology and Infectious Diseases; MRI - magnetic resonance imaging; NICE – National Institute for Health and Care Excellence; NIH - National Institutes of Health; N/R – not reported; PFT - pulmonary function testing; SIGN - Scottish Intercollegiate Guidelines Network; TTE - transthoracic echocardiogram; VTE - venous thromboembolism; WHO – World Health Organization.

### Appendix 3.13 Data extraction table for Italian intersociety consensus on management of long COVID in children

| Clinical guideline and or model of care characteristics  |  |
|--|--|
| <b>Endorsing Organisation</b>  | Italian Society of Pediatrics  |
| <b>Title</b>   | Italian intersociety consensus on management of long COVID in children   |
| <b>Country</b>   | Italy  |
| <b>Date Published</b>  | 9 March 2022   |
| <b>URL</b>   | <a href="https://doi.org/10.1186/s13052-022-01233-6">https://doi.org/10.1186/s13052-022-01233-6</a>  |
| <b>National or regional</b>  | National   |
| <b>Adapted from previous guidelines and or model of care?<br/>If so which guidelines and or model of care was it adapted from?</b> | Definition of long COVID - NICE guidelines, US Centers for Disease Control and Prevention and World Health Organization.   |
| <b>Update(s) planned (including dates)</b>   | N/R  |
| Definition and diagnosis   |  |
| <b>Definition of long COVID used in the guideline and or model of care</b>   | <p><b>Long COVID (NICE guidelines)</b></p> <ul style="list-style-type: none"> <li>▪ Ongoing symptomatic COVID-19 <ul style="list-style-type: none"> <li>○ Symptoms were documented between 4 and 12 weeks after the start of COVID-19.</li> </ul> </li> <li>▪ Post COVID-19 syndrome <ul style="list-style-type: none"> <li>○ Symptoms were still present more than 12 weeks later.</li> </ul> </li> </ul> <p><b>Long COVID (US Centers for Disease Control and Prevention)</b></p> <ul style="list-style-type: none"> <li>▪ Presence of clinical manifestations occurring 4 or more weeks after Infection.</li> </ul> <p><b>Long COVID (World Health Organization)</b></p> <ul style="list-style-type: none"> <li>▪ Post COVID-19 condition occurs in individuals with a history of probable or confirmed SARS-CoV-2 infection, usually 3 months from the onset of COVID-19 with symptoms that last for at least 2 months and cannot be explained by an alternative diagnosis.</li> </ul> <p><b>Recommendation 1:</b></p> <ul style="list-style-type: none"> <li>▪ Long COVID is a clinical condition that includes all pathological manifestations following the acute phase of SARS-CoV-2 infection and which cannot be attributed to causes other than SARS-CoV-2. Although it is not currently possible to precisely define the type and time limits of these manifestations, long COVID can be considered after 3 months from the diagnosis of SARS-CoV-2 infection in the presence of symptoms that last for at least 2 months and which cannot be explained by another diagnosis.</li> </ul> |

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| <p><b>Recommendations for diagnosis of long COVID</b></p>                   | <p><b>Symptoms</b></p> <ul style="list-style-type: none"> <li>▪ Long COVID in children and adolescents should be suspected in presence of persistent;             <ul style="list-style-type: none"> <li>○ headache</li> <li>○ fatigue</li> <li>○ sleep disturbance</li> <li>○ difficulty in concentrating</li> <li>○ abdominal pain</li> <li>○ myalgia</li> <li>○ arthralgia</li> <li>○ chest pain</li> <li>○ stomach pain</li> <li>○ diarrhea</li> <li>○ heart palpitations</li> <li>○ skin lesions</li> </ul> </li> </ul> <p><b>Recommendation 2:</b><br/>Recommend evaluating the presence of symptoms suggestive of long COVID near the end of the acute phase of the disease, between 4 and 12 weeks from this.</p>   |
| <p><b>Management and treatment</b></p>                                      |   |
| <p><b>Recommendations for treatment and or management of long COVID</b></p> | <p><b>Recommendation 4:</b></p> <ul style="list-style-type: none"> <li>▪ Primary care pediatricians should visit all subjects with a suspected or a proven diagnosis of SARS-CoV-2 infection after 4 weeks to check for the presence of symptoms of previously unknown disease.</li> <li>▪ In any case, a further checkup by the primary care pediatrician should be scheduled 3 months after the diagnosis of SARS-CoV-2 infection to confirm normality or to address emerging problems.</li> <li>▪ The subjects who present symptoms of any organic problem must undergo a thorough evaluation of the same.</li> <li>▪ Children and adolescents with clear symptoms of mental stress will need to be followed up by existing local services for problems of this type.</li> </ul> |
| <p><b>Service planning</b></p>  |   |
| <p><b>Recommendations for service planning for long COVID</b></p>           | <p>N/R</p>  |

**Key:** NICE - National Institute for Health and Care Excellence; N/R – not reported.

**Appendix 3.14 Data extraction table for Caring for patients with post-COVID-19 conditions**

| <b>Clinical guideline and or model of care characteristics</b>   |  |
|--|--|
| <b>Endorsing Organisation</b>  | Royal Australian College of General Practitioners  |
| <b>Title</b>   | Caring for patients with post-COVID-19 conditions  |
| <b>Country</b>   | Australia  |
| <b>Date Published</b>  | 5 May 2022   |
| <b>URL</b>   | <a href="http://www.covid19evidence.net.au">www.covid19evidence.net.au</a><br><a href="https://www.racgp.org.au/getattachment/8c5b3936-5551-4b94-81d4-614e2b69da51/Caring-for-patients-with-post-COVID-19-conditions.aspx">https://www.racgp.org.au/getattachment/8c5b3936-5551-4b94-81d4-614e2b69da51/Caring-for-patients-with-post-COVID-19-conditions.aspx</a>  |
| <b>National or regional</b>  | National   |
| <b>Adapted from previous guidelines and or model of care?<br/>If so which guidelines and or model of care was it adapted from?</b> | N/A  |
| <b>Update(s) planned (including dates)</b>   | N/R  |
| <b>Definition and diagnosis</b>  |  |
| <b>Definition of long COVID used in the guideline and or model of care</b>   | <p>This guide contains information for general practitioners and their teams, who are providing care for patients who have previously tested positive to COVID-19 or have a history suggestive of undiagnosed COVID-19 and have – or are at risk of – post– COVID-19 conditions at any point after the initial acute infection.</p> <p><b>Post COVID-19 condition</b></p> <ul style="list-style-type: none"> <li>WHO definition: Post COVID-19 condition occurs in individuals with a history of probable or confirmed SARS-CoV-2 infection, usually 3 months from the onset of COVID-19 with symptoms and that last for at least 2 months and cannot be explained by an alternative diagnosis. Common symptoms include fatigue, shortness of breath, cognitive dysfunction but also others and generally have an impact on everyday functioning. Symptoms may be new onset following initial recovery from an acute COVID-19 episode or persist from the initial illness. Symptoms may also fluctuate or relapse over time.</li> </ul> <p><b>Chronic COVID-19 or Post–COVID syndrome</b></p> <ul style="list-style-type: none"> <li>Illness extending beyond 12 weeks from initial symptoms.</li> </ul> <p><b>Long COVID</b></p> <ul style="list-style-type: none"> <li>NICE definition: COVID-19 symptoms following acute illness, irrespective of how long the symptoms take to resolve, and could be used to refer to either of the above 2 conditions.</li> </ul> |
| <b>Recommendations for diagnosis of long COVID</b>   | <p><b>Post-acute COVID-19 symptoms</b></p> <ul style="list-style-type: none"> <li>Common symptoms include:</li> </ul>  |



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|  | <ul style="list-style-type: none"> <li>○ fatigue</li> <li>○ dyspnoea</li> <li>○ joint pain</li> <li>○ chest pain</li> <li>○ cough</li> <li>○ change in sense of smell or taste</li> <li>○ cognitive disturbances</li> <li>○ hoarse voice</li> <li>■ Less common symptoms include: <ul style="list-style-type: none"> <li>○ insomnia</li> <li>○ low-grade fevers</li> <li>○ headaches</li> <li>○ neurocognitive difficulties</li> <li>○ myalgia and weakness</li> <li>○ gastrointestinal symptoms</li> <li>○ rash</li> <li>○ depression</li> </ul> </li> <li><b>Significant COVID-19-specific sequelae</b> <ul style="list-style-type: none"> <li>■ Pulmonary: <ul style="list-style-type: none"> <li>○ persisting interstitial lung disease</li> <li>○ impaired lung function</li> <li>○ pneumonia/lung cavitation</li> <li>○ dyspnoea</li> <li>○ complications of intubation/ventilation, including chronic cough, hoarse voice</li> </ul> </li> <li>■ Endocrine: <ul style="list-style-type: none"> <li>○ deterioration of diabetic control</li> <li>○ osteoporosis due to prolonged immobilisation</li> <li>○ diabetic ketoacidosis without known diabetes mellitus</li> </ul> </li> <li>■ Cardiovascular: <ul style="list-style-type: none"> <li>○ myocardial infarction</li> <li>○ myocarditis</li> <li>○ pericarditis</li> <li>○ arrhythmia</li> <li>○ heart failure</li> <li>○ VTE</li> </ul> </li> <li>■ Mental health:</li> </ul> </li> </ul> |
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|  | <ul style="list-style-type: none"><li>○ worsening of cognitive decline</li><li>○ depression</li><li>○ anxiety</li><li>○ post-traumatic stress disorder following severe illness</li><li>○ insomnia/sleep disturbances</li><li>■ Neurological:<ul style="list-style-type: none"><li>○ stroke</li><li>○ cognitive impairment</li><li>○ encephalopathy</li><li>○ epilepsy</li><li>○ myelitis</li><li>○ critical care neuropathy/myopathy</li><li>○ chronic malaise</li><li>○ loss of taste and smell</li><li>○ paraesthesia</li><li>○ cognitive blunting (brain fog)</li></ul></li><li>■ Post-intensive care syndrome:<ul style="list-style-type: none"><li>○ dyspnoea</li><li>○ anxiety</li><li>○ depression</li><li>○ prolonged pain</li><li>○ reduced physical function</li></ul></li><li>■ Haematological:<ul style="list-style-type: none"><li>○ hypercoagulable state</li><li>○ anaemia</li><li>○ VTE</li></ul></li><li>■ Musculoskeletal:<ul style="list-style-type: none"><li>○ diffuse myalgia</li><li>○ joint pain</li></ul></li><li>■ Rheumatological:<ul style="list-style-type: none"><li>○ post-viral syndrome similar to chronic fatigue syndrome</li></ul></li><li>■ Paediatric:<ul style="list-style-type: none"><li>○ paediatric inflammatory multisystem syndrome temporally associated with SARS-CoV-2</li></ul></li><li>■ Dermatological:<ul style="list-style-type: none"><li>○ hair loss</li><li>○ skin rash</li></ul></li></ul> |
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|  | <ul style="list-style-type: none"> <li>▪ <b>General:</b> <ul style="list-style-type: none"> <li>○ cardiac/respiratory/musculoskeletal deconditioning</li> <li>○ reduced nutritional status and weight loss</li> <li>○ low-grade fevers</li> <li>○ renal impairment/acute kidney injury</li> <li>○ gastrointestinal disturbances</li> <li>○ liver dysfunction</li> <li>○ pressure sores</li> <li>○ reduced quality of life</li> </ul> </li> </ul> <p><b>General practice presentations of post-acute COVID-19</b></p> <ul style="list-style-type: none"> <li>▪ Scenarios are likely to be based on: <ul style="list-style-type: none"> <li>○ non-specific post-viral symptoms, particularly fatigue, breathlessness, persistent cough and cognitive dysfunction</li> <li>○ specific serious sequelae resulting from the acute infection, or as delayed complications</li> <li>○ recovery following severe illness that required intensive care management</li> <li>○ mental health impacts of the acute illness, stigma, ongoing symptoms and functional impairment.</li> </ul> </li> <li>▪ For patients with ongoing symptomatic COVID-19 or suspected post-COVID-19 conditions, a holistic, person-centred approach should be used, including a comprehensive clinical history and appropriate examination that involves assessing physical, cognitive, psychological and psychiatric symptoms, as well as functional abilities.</li> <li>▪ Consider and exclude serious complications and possible alternative causes of ongoing symptoms, such as anaemia. Investigate new or worsening symptoms that could indicate delayed sequelae, such as VTE, cardiac complications or pneumonia.</li> </ul> <p><b>Identifying patients at risk of post-COVID-19 conditions</b></p> <ul style="list-style-type: none"> <li>▪ Early review after acute illness is recommended when requested in the discharge summary, when a person is determined to be at higher risk of post-COVID-19 conditions or when the patient is still experiencing non-specific post-viral symptoms.</li> <li>▪ Patient assessment should include: <ul style="list-style-type: none"> <li>○ history of acute COVID-19 (suspected or confirmed)</li> <li>○ nature and severity of previous and current symptoms</li> <li>○ timing and duration of symptoms since the start of acute COVID-19</li> <li>○ history of other health conditions</li> <li>○ exacerbation of pre-existing conditions</li> <li>○ mental health and wellbeing</li> <li>○ available support</li> </ul> </li> </ul> <p><b>Escalating care for patients with red flag symptoms</b></p> |
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|   | <ul style="list-style-type: none"> <li>▪ Red flag symptoms and vital signs are suggestive of severe disease. Patients with red flag symptoms should be immediately assessed. They might require urgent care in a hospital emergency department or by ambulance services.</li> <li>▪ Red flag symptoms include: <ul style="list-style-type: none"> <li>○ severe, new onset, or worsening breathlessness or hypoxia</li> <li>○ syncope</li> <li>○ unexplained chest pain, palpitations or arrhythmias</li> <li>○ new delirium, or focal neurological signs or symptoms</li> </ul> </li> </ul>   |
| <b>Management and treatment</b>   |   |
| <p><b>Recommendations for treatment and or management of long COVID</b></p> | <p><b>Providing patient education</b></p> <p>Arrange a time with the patient to discuss:</p> <ul style="list-style-type: none"> <li>▪ How this health issue intersects with their other personal health history.</li> <li>▪ Common symptoms they might experience after acute COVID-19.</li> <li>▪ How long they might experience symptoms (most likely to resolve within 12 weeks).</li> <li>▪ How to monitor and manage their symptoms at home. Patients can record their symptoms in their 'My post-COVID-19 symptom diary' available in the patient resource, Managing post-COVID-19 symptoms.</li> <li>▪ Symptoms that might require medical care (e.g certain new or worsening symptoms) and where to seek care if they experience these symptoms.</li> <li>▪ What to expect in the weeks and months following acute COVID-19, including that symptom resolution will be different for each person and that symptoms might fluctuate or change over time.</li> <li>▪ Supports for lifestyle interventions, such as physical activity, nutrition or counselling, to assist with return to usual activities and management of comorbid physical and mental health conditions.</li> <li>▪ Vaccination post-infection if they have not already been vaccinated, or are due for a booster dose.</li> <li>▪ Risks of reinfection and how they can manage this risk.</li> <li>▪ When having these discussions: <ul style="list-style-type: none"> <li>○ recognise the patient's health beliefs</li> <li>○ it is important to acknowledge that the persons symptoms are real</li> <li>○ acknowledge the mental health impacts of COVID-19 and the isolation experience, demonstrating empathy</li> <li>○ tailor the message to fit the patient's needs, including their English and health literacy</li> <li>○ ensure you use an accredited interpreter if the patient requires an interpreter</li> <li>○ ask the patient if they have any specific concerns that they wish to discuss</li> <li>○ gain an understanding of the patient's expectations and needs, and develop a decision-making process and management plan together, if required</li> <li>○ ensure the patient has access to required supports</li> </ul> </li> </ul> |

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|  | <ul style="list-style-type: none"> <li>▪ It is important to ensure that your patient understands that having some post-COVID-19 symptoms does not mean that they are still infectious.</li> <li>▪ Empower your patient so that they feel comfortable in reassuring their family, friends and employers about this issue, acknowledging that it is natural for people to find these conversations difficult.</li> <li>▪ Encourage patients and their families to ask questions about post-COVID-19-symptoms. Ensure your patient understands the possible fluctuations in severity and support requirements so that they are fully informed prior to making decisions about their care.</li> </ul> <p><b>Management of common symptoms</b></p> <ul style="list-style-type: none"> <li>▪ Management of presentations of post-COVID-19 conditions will usually be pragmatic and symptomatic. Support your patient to maximise their personal wellbeing through diet, exercise and sleep.</li> <li>▪ Where possible, optimise the management of the patient’s other chronic conditions.</li> <li>▪ Identify other social factors that could intersect with their personal health and wellbeing, including smoking, alcohol intake, drug use, risk of mental health issues, risk of family and intimate partner violence, and risk of social isolation.</li> <li>▪ Management should be guided by the patient’s specific clinical circumstances and be evidence based. Specialist referral should be undertaken, as required.</li> <li>▪ Collaborate with the patient to develop an individualised management plan to support their recovery.</li> <li>▪ Your initial assessment will help inform your management plan. Your patient could benefit from allied health input. Consider collaborating with community and hospital-based allied health, rehabilitation medicine and geriatric medicine services to support individual management planning where appropriate. This might include: <ul style="list-style-type: none"> <li>○ physiotherapists</li> <li>○ exercise physiologists</li> <li>○ occupational therapists</li> <li>○ dietitians</li> <li>○ speech pathologists</li> <li>○ psychologists</li> <li>○ occupational and environmental physicians</li> <li>○ rehabilitation medicine physicians</li> <li>○ geriatric medicine physicians</li> <li>○ rehabilitation medicine services including outpatients, day rehabilitation and inpatient rehabilitation</li> <li>○ geriatric medicine services including outpatients, and geriatric evaluation and management units</li> </ul> </li> </ul> <p><b>Recommendations relating to management: specific conditions</b></p> <ul style="list-style-type: none"> <li>▪ Breathlessness: <ul style="list-style-type: none"> <li>○ optimise management of pre-existing respiratory conditions</li> <li>○ recommend respiratory muscle conditioning (pulmonary rehabilitation)</li> </ul> </li> </ul> |
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|  | <ul style="list-style-type: none"> <li>○ consider chest X-ray at 12 weeks for patients who have had significant respiratory illness</li> <li>○ corticosteroids could be considered for inflammatory lung disease on the advice of a respiratory physician</li> <li>○ recommend gradual commencement or return to symptom-limited exercise guided by tertiary-trained exercise professionals</li> <li>○ referral to a speech pathologist for management of chronic cough, hoarse voice or dysphagia</li> <li>○ consider home pulse oximetry measurement</li> <li>○ referral to an Accredited Practising Dietitian if symptoms interfere with nutrition, and speech pathology if dysphagia is present.</li> <li>■ Fatigue: <ul style="list-style-type: none"> <li>○ maximise self-care, sleep, relaxation and nutrition</li> <li>○ recommend that patients pace and be selective when prioritising daily activities</li> <li>○ recommend caution with return to exercise (reduce if there is any increase in symptoms)</li> <li>○ a monitored return to exercise can be supported by an exercise physiology, physiotherapy or rehabilitation referral</li> <li>○ if fatigue is causing difficulty with ADLs, recommend energy conservation techniques and home visits by an occupational therapist or rehabilitation service</li> </ul> </li> <li>■ Chest pain: <ul style="list-style-type: none"> <li>○ exclude acute coronary syndrome, myocarditis, pericarditis, pulmonary effusion or pulmonary embolism, and arrhythmia</li> <li>○ provide education regarding symptoms of concern</li> <li>○ patients who have had myocarditis or pericarditis as a component of their acute illness should abstain from vigorous exercise for 3–6 months, and athletes should have cardiology supervision for return to training</li> <li>○ refer for graded increase in low-to-moderate activity to increase mobility, exercise capacity and quality of life; this should be facilitated by a physiotherapist or exercise physiologist, or cardiac rehabilitation programme</li> </ul> </li> <li>■ Headaches, low-grade fevers and myalgia: <ul style="list-style-type: none"> <li>○ exclude COVID-19 reinfection or recrudescence</li> <li>○ prescribe simple supportive measures and analgesia or antipyretics, as needed</li> <li>○ check for secondary infections and prescribe antibiotics, as appropriate</li> </ul> </li> <li>■ Neurocognitive difficulty: <ul style="list-style-type: none"> <li>○ if severe enough to cause difficulty with ADLs, consider cognitive testing, occupational therapy support and speech pathology support for cognitive communication impairment</li> </ul> </li> <li>■ Depression/anxiety: <ul style="list-style-type: none"> <li>○ provide information about post-COVID-19 recovery</li> </ul> </li> </ul> |
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|  | <ul style="list-style-type: none"> <li>○ use existing standardised screening tools</li> <li>○ address multifactorial contributors that might require assistance with pain management, independence with ADLs, financial and other social supports, and loneliness</li> <li>○ facilitate access to mental health services or online support if patient is unwilling to access face-to-face counselling</li> <li>○ encourage individualised moderate-intensity exercise initiated and supervised by a tertiary-trained exercise professional</li> <li>○ refer to an Accredited Practising Dietitian for nutrition support and access to food services</li> <li>■ Thrombosis risk and contraceptive choice:             <ul style="list-style-type: none"> <li>○ COVID-19 causes a hypercoagulable state in some people, which might worsen the VTE risk associated with combined hormonal contraception. The incidence of VTE in biological females of reproductive age with COVID-19 infection is currently not known</li> <li>○ patients should be advised of this risk to allow informed choice of contraceptive option</li> <li>○ for biological females who have had mild or moderate COVID-19 and stopped oral menopausal hormone therapy, also known as hormone replacement therapy, if recommencing, consider using a transdermal preparation</li> <li>○ for biological females who have had COVID-19 and who are taking oestrogen-containing contraception, manage these medications as per usual care</li> <li>○ for biological females who have stopped or suspended contraception when they have contracted COVID-19, contraception can be restarted when acute symptoms have resolved.</li> </ul> </li> </ul> |
| <b>Service planning</b>                                    |  |
| <b>Recommendations for service planning for long COVID</b> | N/R  |

**Key:** ADLs - activities of daily living; NICE - National Institute for Health and Care Excellence; N/A - not applicable; N/R – not reported; VTE - venous thromboembolism; WHO- World Health Organization.

**Appendix 3.15 Data extraction table for Australian guidelines for the clinical care of people with COVID-19**

| <b>Clinical guideline and or model of care characteristics</b>   |  |
|--|--|
| <b>Endorsing Organisation</b>  | Australian National COVID-19 Clinical Evidence Taskforce   |
| <b>Title</b>   | Australian guidelines for the clinical care of people with COVID-19  |
| <b>Country</b>   | Australia  |
| <b>Date Published</b>  | 8 May 2022   |
| <b>URL</b>   | <a href="https://app.magicapp.org/#/guideline/L4Q5An">https://app.magicapp.org/#/guideline/L4Q5An</a>  |
| <b>National or regional</b>  | National   |
| <b>Adapted from previous guidelines and or model of care?<br/>If so which guidelines and or model of care was it adapted from?</b> | Early recommendations are primarily adapted from other guidelines and/or based on the consensus of the guideline panel.<br><br>NICE, WHO, NSW HealthPathway, CDC   |
| <b>Update(s) planned (including dates)</b>   | v64 was published on 16 September 2022 with the last evidence search conducted on 26 August 2022.<br>In addition to this broad COVID-19 guideline, the Taskforce states it is currently reviewing the evidence to develop recommendations and flowcharts for a guideline under the title of Caring for people with COVID-19, updated 16 September 2022.  |
| <b>Definition and diagnosis</b>  |  |
| <b>Definition of long COVID used in the guideline and or model of care</b>   | <b>Post-COVID-19 condition/syndrome:</b> <ul style="list-style-type: none"> <li>Signs and symptoms that develop during or after an infection consistent with COVID-19, continue for more than 12 weeks and are not explained by an alternative diagnosis. It usually presents with clusters of symptoms, often overlapping, which can fluctuate and change over time and can affect any system in the body. Post COVID-19 condition may be considered before 12 weeks while the possibility of an alternative underlying disease is also being assessed.</li> </ul>  |
| <b>Recommendations for diagnosis of long COVID</b>   | <ul style="list-style-type: none"> <li>Due to the broad range of effects of post-COVID-19, a biopsychosocial approach to care, within the local context, is important. Validate the patient's experience and offer information about the symptoms that they are experiencing, including management options.</li> </ul> <p><b>Good practice statements</b></p> <ul style="list-style-type: none"> <li>The following recommendations should be applied after considering features of the individual, their preferences and the context in terms of rurality/remoteness, public health responses and proximity to rehabilitation or higher-level care. For those needing active rehabilitation, involving a larger centre or specialist care could be considered. Use of virtual care, including telehealth, should be considered.</li> </ul> <p><b>Initial Investigations:</b></p> |



- Confirm that the person had COVID-19 (by checking that they had a positive PCR test), or is likely to have had COVID-19 (by checking that they have had symptoms consistent with a SARS-CoV-2 infection and/or known contact with a positive case or high-risk setting). Document details of the acute illness.
- Check the current symptoms and ask the person about their concerns, functioning and wishes in terms of their needs.
- Assess whether the current symptoms are likely to be related to acute COVID-19.
- Assess whether the symptoms may be related to, or are exacerbated by, comorbid conditions.
- There is no definitive test for post-COVID-19. To avoid adding burden to the person, limit investigations to those that are necessary for determining care. *(adapted from CDC)*

### **Symptom-Based Testing**

#### ***Evidence-Based Recommendations - Conditional***

- Decisions about blood tests should be guided by the person's symptoms. If clinically indicated, offer blood tests, which may include a full blood count, kidney and liver function tests, C-reactive protein, ferritin, B-type natriuretic peptide, hemoglobin A1c and thyroid function tests. *(adapted from NICE)*
- If appropriate, offer an exercise tolerance test suited to the person's ability (e.g. the 1-minute sit-to-stand test). During the exercise test, record level of breathlessness, heart rate and oxygen saturation. Follow an appropriate protocol to carry out the test safely. *(adapted from NICE)*
- Offer a chest X-ray by 12 weeks after acute COVID-19 only if the person has continuing respiratory symptoms and it is clinically indicated. Chest X-ray appearances alone should not determine the need for referral for further care. *(adapted from NICE)*

#### ***Consensus-Based Recommendations***

- For people with postural symptoms, e.g. palpitations or dizziness on standing, carry out lying and standing blood pressure and heart rate recordings (3-minute active stand test for orthostatic hypotension, or 10 minutes if you suspect postural tachycardia syndrome, or other forms of orthostatic intolerance). *(adapted from NICE)*

#### ***Red flag symptoms (adapted from NSW HealthPathway)***

- Exclude red flag symptoms that could indicate the need for emergency assessment for serious complications of COVID-19. Red flag symptoms include;
  - severe, new onset, or worsening breathlessness or hypoxia
  - syncope
  - unexplained chest pain
  - palpitations or arrhythmias
  - new delirium
  - focal neurological signs or symptoms

#### ***Consensus recommendation:***

The following symptoms and signs have been described by people with post-COVID-19 infection:

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|  | <ul style="list-style-type: none"> <li>▪ Pulmonary symptoms: <ul style="list-style-type: none"> <li>○ shortness of breath</li> <li>○ cough</li> </ul> </li> <li>▪ Neurological symptoms: <ul style="list-style-type: none"> <li>○ fatigue</li> <li>○ headache</li> <li>○ cognitive dysfunction</li> <li>○ sleep disturbance</li> <li>○ loss of smell</li> <li>○ paraesthesia</li> </ul> </li> <li>▪ Hair loss</li> <li>▪ Skin conditions</li> <li>▪ Renal disease</li> <li>▪ Thromboembolism</li> <li>▪ Psychological symptoms: <ul style="list-style-type: none"> <li>○ anxiety</li> <li>○ depression</li> <li>○ mood swings</li> <li>○ <i>Note that fatigue and sleep disturbance may also indicate the emergence of a mental health condition</i></li> </ul> </li> <li>▪ Cardiac symptoms: <ul style="list-style-type: none"> <li>○ chest pain</li> </ul> </li> <li>▪ Musculoskeletal symptoms: <ul style="list-style-type: none"> <li>○ non-specific pain</li> <li>○ myalgia</li> </ul> </li> <li>▪ Fever: <ul style="list-style-type: none"> <li>○ low-grade fevers</li> </ul> </li> <li>▪ Reduced activity and functional level</li> <li>▪ Reduced nutritional status and weight loss</li> </ul> <p><b><i>Post-intensive care syndrome</i></b></p> <ul style="list-style-type: none"> <li>▪ This refers to one or more of the following symptoms that people experience following care in an intensive care unit: <ul style="list-style-type: none"> <li>○ anxiety</li> <li>○ depression</li> <li>○ cognitive impairment</li> <li>○ memory loss</li> </ul> </li> </ul> |
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|   | <ul style="list-style-type: none"> <li>○ muscle weakness</li> <li>○ dysphagia</li> <li>○ reduced quality of life</li> </ul> <p><b>Multisystem inflammatory syndrome</b></p> <ul style="list-style-type: none"> <li>■ In some people, both adults and children, symptoms corresponding to multisystem inflammatory syndrome have been reported.</li> </ul>   |
| <b>Management and treatment</b>   |   |
| <p><b>Recommendations for treatment and or management of long COVID</b></p> | <p><b>Management in patients with continuing symptoms after COVID-19</b></p> <p><b>Consensus Recommendations</b></p> <ul style="list-style-type: none"> <li>■ In patients with continuing symptoms after COVID-19, use established symptom management approaches (e.g. breathing retraining to improve symptoms of dyspnoea). <ul style="list-style-type: none"> <li>○ Evidence of specific management post COVID-19 is not available. Established symptom management approaches are likely to be beneficial.</li> <li>○ Use existing clinical guidelines to guide symptom management.</li> </ul> </li> <li>■ In patients with post-exertional fatigue, use a conservative physical rehabilitation plan involving consultation with physiotherapy or exercise physiology for cautious initiation and pacing of activity or movement. <i>(Adapted from CDC)</i> <ul style="list-style-type: none"> <li>○ For most patients, gradual return to exercise as tolerated may be beneficial.</li> <li>○ Additional caution and specialist review should be sought before commencing exercise programs in patients who are known to have myocarditis.</li> <li>○ A rehabilitation plan, where appropriate, might include physical and occupational therapy, speech and language therapy, vocational therapy, as well as neurological rehabilitation for cognitive symptoms.</li> <li>○ Consider individual factors and access issues in determining location for further treatment or rehabilitation (e.g., home-based, telehealth or face-to-face options).</li> <li>○ Use local and regional protocols and HealthPathways to determine optimal referral pathways.</li> </ul> </li> <li>■ In patients with persistent symptoms or functional impairment following COVID-19, begin rehabilitation as soon as possible, as appropriate to the individual's setting and tolerance. <ul style="list-style-type: none"> <li>○ A rehabilitation plan, where appropriate, might include physical and occupational therapy, speech and language therapy, vocational therapy, as well as neurological rehabilitation for cognitive symptoms.</li> <li>○ Consider using a chronic disease plan, mental healthcare plan or other enhanced care plan to facilitate access to multidisciplinary care.</li> <li>○ Consider individual factors and access issues in determining location for further treatment or rehabilitation (e.g. home-based, telehealth or face-to-face options).</li> <li>○ Use local and regional protocols and HealthPathways to determine optimal referral pathways.</li> </ul> </li> </ul> |

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|   | <ul style="list-style-type: none"> <li>▪ In patients with continuing symptoms after COVID-19, monitor and optimise management of underlying medical conditions. <i>(Adapted from CDC)</i></li> <li>▪ In patients with continuing symptoms after COVID-19, monitor and manage lifestyle factors (e.g. smoking, nutrition, sleep, alcohol use and physical activity).</li> <li>▪ Schedule regular review as necessary and discuss patient function and symptomatology. <ul style="list-style-type: none"> <li>○ Where possible, use standardised tools to monitor changes in function and symptomology.</li> </ul> </li> <li>▪ Give people information on COVID-19 vaccines and encourage them to follow current official guidance for vaccination. Explain that it is not known if vaccines have any effect on ongoing symptomatic COVID-19 or post-COVID-19 condition. <i>(Adapted from NICE)</i></li> <li>▪ In patients with continuing symptoms after COVID-19, do not use emerging or unproven therapies outside of randomised trials with appropriate ethical approval.</li> </ul> <p>Our understanding of effective management approaches is still emerging. As such, recommendations for the management of people with post-COVID-19 will be updated here as new evidence emerges. In the interim, we direct readers to the <a href="#">Post-COVID-19 flowchart</a>. This flowchart outlines aspects of care and treatment based on current best-practice approaches.</p> |
| <b>Service planning</b>   |   |
| <p><b>Recommendations for service planning for long COVID</b></p> | <p><b>Practice Points</b></p> <ul style="list-style-type: none"> <li>▪ The primary healthcare team is well placed to coordinate person-centred care and should remain a central point in the care team along with the person's caregiver or significant other. Best practice would include a multidisciplinary team. This could be accessed through general practice, community health, rehabilitation programs or post-COVID-19 clinics, where these are available. Use case conferences to facilitate coordinated care.</li> </ul>  |

**Key:** CDC - Centres for Disease Control and Prevention; NICE - The National Institute for Health and Care Excellence; NSW Healthpathway - New South Wales Healthpathway; PCR - polymerase chain reaction.

### Appendix 3.16 Data extraction table for Clinical practice guide for assessment and management of adults with post-acute sequelae of COVID-19 Guidance for New South Wales health clinicians

| Clinical guideline and or model of care characteristics  |   |
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| <b>Endorsing Organisation</b>  | Agency for Clinical Innovation, NSW government  |
| <b>Title</b>   | Clinical practice guide for assessment and management of adults with PASC Guidance for NSW health clinicians  |
| <b>Country</b>   | Australia   |
| <b>Date Published</b>  | 31 May 2022   |
| <b>URL</b>   | <a href="https://aci.health.nsw.gov.au/_data/assets/pdf_file/0011/726878/ACI-CPG-for-assessment-and-management-of-adults-with-post-acute-sequelae-of-COVID-19.pdf">Living Evidence - post acute sequelae of COVID-19 (long COVID)   Agency for Clinical Innovation (nsw.gov.au) https://aci.health.nsw.gov.au/_data/assets/pdf_file/0011/726878/ACI-CPG-for-assessment-and-management-of-adults-with-post-acute-sequelae-of-COVID-19.pdf</a>  |
| <b>National or regional</b>  | Regional  |
| <b>Adapted from previous guidelines and or model of care?<br/>If so which guidelines and or model of care was it adapted from?</b> | This guide is consistent with the HealthPathway Post COVID-19 Conditions and the Royal Australian College of General Practitioners document Caring for patients with post-COVID-19 conditions. The HealthPathway was developed in collaboration with the NSW COVID-19 Rehabilitation Community of Practice. It has been adopted with local adaptation in most primary health networks across NSW for use by general practitioners and practice nurses.  |
| <b>Update(s) planned (including dates)</b>   | Living document that will continue to be updated in line with emerging evidence. Last update was 14 July 2022.  |
| Definition and diagnosis   |   |
| <b>Definition of long COVID used in the guideline and or model of care</b>   | <p><b>PASC</b></p> <ul style="list-style-type: none"> <li>▪ Also referred to as 'post-acute COVID-19 condition', 'post COVID-19 syndrome' or 'long COVID' is defined by the WHO as: "the condition that occurs in individuals with a history of probable or confirmed SARS-CoV-2 infection, usually: <ul style="list-style-type: none"> <li>○ 3 months from the onset of COVID-19;</li> </ul> </li> </ul> <p>AND</p> <ul style="list-style-type: none"> <li>○ with symptoms that last for at least 2 months and cannot be explained by an alternative diagnosis"</li> </ul> |
| <b>Recommendations for diagnosis of long COVID</b>   | <p><b>Most commonly reported symptoms of PASC</b></p> <ul style="list-style-type: none"> <li>▪ Respiratory: <ul style="list-style-type: none"> <li>○ breathlessness</li> <li>○ cough</li> </ul> </li> <li>▪ Cardiovascular: <ul style="list-style-type: none"> <li>○ chest tightness</li> <li>○ chest pain</li> <li>○ palpitations</li> </ul> </li> </ul>   |

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|  | <ul style="list-style-type: none"><li>○ postural hypotension</li><li>○ postural orthostatic tachycardia syndrome (POTS)</li><li>■ General:<ul style="list-style-type: none"><li>○ fatigue</li><li>○ fever</li><li>○ pain</li></ul></li><li>■ Neurological:<ul style="list-style-type: none"><li>○ autonomic dysfunction</li><li>○ cognitive impairment ('brain fog', loss of concentration or memory issues)</li><li>○ delirium (especially in older populations)</li><li>○ dizziness</li><li>○ headache</li><li>○ mobility impairment</li><li>○ peripheral neuropathy symptoms including neuropathic pain</li><li>○ sleep disturbance (independent of symptoms of depression based on alteration of circadian rhythm)</li><li>○ visual disturbance</li></ul></li><li>■ Gastrointestinal:<ul style="list-style-type: none"><li>○ abdominal pain</li><li>○ diarrhoea</li><li>○ nausea and vomiting</li><li>○ weight loss and reduced appetite</li></ul></li><li>■ Musculoskeletal:<ul style="list-style-type: none"><li>○ joint pain</li><li>○ muscle pain</li></ul></li><li>■ Ear, nose and throat:<ul style="list-style-type: none"><li>○ dysphagia</li><li>○ dysphonia</li><li>○ earache</li><li>○ loss of taste and/or smell</li><li>○ nasal congestion</li><li>○ sore throat</li><li>○ yinnitus</li><li>○ vertigo</li></ul></li><li>■ Dermatological:<ul style="list-style-type: none"><li>○ hair loss</li><li>○ skin rashes</li></ul></li></ul> |
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|  | <ul style="list-style-type: none"> <li>▪ Psychological or psychiatric: <ul style="list-style-type: none"> <li>○ anxiety</li> <li>○ depression</li> <li>○ post-traumatic stress disorder</li> </ul> </li> </ul> <p><b>Red Flags- refer to local emergency department for urgent assessment and treatment</b></p> <ul style="list-style-type: none"> <li>▪ Focal neurological signs or symptoms</li> <li>▪ New confusion</li> <li>▪ Palpitations or arrhythmia</li> <li>▪ Severe, new onset or worsening breathlessness</li> <li>▪ Syncope</li> <li>▪ Unexplained chest pain</li> </ul> <p><b>Comprehensive patient assessment</b></p> <ul style="list-style-type: none"> <li>▪ Regardless of the care setting in which a person presents with PASC, a holistic, person-centred approach to patient assessment is required. A comprehensive clinical history and appropriate examination should include: <ul style="list-style-type: none"> <li>○ History of acute COVID-19 (suspected or confirmed)</li> <li>○ The nature and severity of previous and current symptoms – This should include documentation of objective markers of disease severity such as requirement for ICU admission, ICU and hospital length of stay (if applicable), the use of invasive or non-invasive ventilation or extracorporeal membrane oxygenation, arterial or venous thromboembolic complications, sepsis and any opportunistic infections in context of immunomodulators</li> <li>○ Timing and duration of symptoms since the onset of acute COVID-19 illness.</li> <li>○ History of other health conditions</li> <li>○ Exacerbation of pre-existing conditions</li> <li>○ Social determinants of health assessment (e.g. interpersonal connections, work, finances and lifestyle factors)</li> <li>○ COVID-19 vaccination status</li> </ul> </li> <li>▪ It may assist for a family member, caregiver, or trusted friend to support the patient in this assessment.</li> </ul> <p><b>Patient-reported outcome measures</b></p> <ul style="list-style-type: none"> <li>▪ Important part of the patient assessment is measuring the severity and impact of the symptoms on a person’s level of functioning and degree of impairment experienced; <ul style="list-style-type: none"> <li>○ COVID-19 Yorkshire Rehabilitation Scale*</li> <li>○ PROMIS-29</li> <li>○ EQ-5D- 5L</li> </ul> </li> </ul> <p><b>Assessment of Individual Signs and Symptoms</b></p> <p><b><i>Fatigue</i></b></p> |
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|  | <ul style="list-style-type: none"> <li>▪ Assessment of the pattern and character of fatigue is required to exclude other diagnoses, such as depression, anxiety, drug or substance abuse and sleep disturbance. The assessment should consider other potential factors leading to fatigue and loss of motivation. The impact of fatigue on the patient's life, function and activities, such as work, education, mobility and independence, should be explored.</li> <li>▪ Post-COVID-19 fatigue is often associated with respiratory symptoms including shortness of breath and a cough.</li> <li>▪ Investigations for fatigue to rule out any secondary causes may include routine haematology and biochemistry, including full blood count, iron studies, urea and electrolytes, thyroid function tests, liver function tests, bone profile, erythrocyte sedimentation rate, C-reactive protein and vitamin B12 measures. Early morning serum cortisol and a nutritional profile may also be indicated, particularly if dietary history is suggestive of issues and/or no other abnormalities are detected via routine pathology.</li> <li>▪ Where the presence of any secondary cause of fatigue has been excluded, a validated scale or tool may be used to assess and monitor symptoms of fatigue. These can aid in assessing progress and response to treatment. Suitable tools include: <ul style="list-style-type: none"> <li>○ Fatigue Severity Scale</li> <li>○ PROMIS-29 (fatigue questions 13-16)</li> <li>○ Brief Fatigue Inventory</li> </ul> </li> <li>▪ In those with a history of daytime sleepiness, establish a sleep history and screen for sleep apnoea. If at high risk for sleep apnoea, the person should be referred for polysomnography.</li> </ul> <p><b>Breathlessness</b></p> <ul style="list-style-type: none"> <li>▪ People recovering from an acute COVID-19 illness who were admitted to hospital and required respiratory support, such as high flow oxygen, continuous positive airway pressure, or intubation, are at high risk of persistent exertional breathlessness and reduced exercise tolerance</li> <li>▪ Assessment of breathlessness should consider the severity of acute illness, acute complications and the respiratory support that was required during the acute illness, e.g. the use of mechanical or non-invasive ventilation. Review of a person's medical history should specifically include a review of comorbid cardiac and respiratory disease</li> <li>▪ Formal assessment of the severity of a patient's breathlessness should be made. Assessment tools include; <ul style="list-style-type: none"> <li>○ Dyspnoea-12 score</li> <li>○ Modified Medical Research Council Dyspnoea Scale</li> <li>○ Modified 0-10 Borg Dyspnoea Scale</li> </ul> </li> <li>▪ Persistent breathlessness eight weeks (or more) following COVID-19 illness should be assessed with: <ul style="list-style-type: none"> <li>○ CXR, which should be compared with previous CXRs where available</li> <li>○ Spirometry</li> <li>○ DLCO</li> </ul> </li> </ul> |
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|  | <ul style="list-style-type: none"> <li>■ In those with persistent breathlessness, a measure of exercise tolerance should be made with a submaximal exercise test. These tests can be performed in some lung function laboratories, by physiotherapists and in pulmonary rehabilitation services. Clinical judgement should be exercised in recommending exercise tolerance tests in people with significant fatigue due to the risk of post-exertional malaise. Relevant tests include: <ul style="list-style-type: none"> <li>○ A 6-minute walk test with continuous monitoring of oxygen saturation</li> <li>○ A rapid exertional desaturation test, e.g, one minute sit-to-stand test or 40 step test. This test should only be performed if oxygen saturation at rest is greater than 95%. The test should be discontinued if the patient feels unwell. If oxygen saturation decreases by 3% or more, this is indicative of significant lung disease and the patient should be referred to respiratory medicine.</li> </ul> </li> <li>■ Refer patients with persistent breathlessness, abnormal CXR or lung function to respiratory physician or clinic. In those patients with worsening of breathlessness and infiltrates on CXR consider complicating cardiac failure, or the development of interstitial lung disease.</li> <li>■ In those who present with new onset breathlessness, especially if associated with pleuritic chest or pain, calf swelling and pain, and no new changes on CXR, consider deep vein thrombosis and pulmonary embolism.</li> <li>■ Cardiac disease may present with worsening dyspnoea which may be accompanied by chest pain. Consider investigations such as an electrocardiogram and echocardiogram where clinically indicated, especially in those with a history of heart disease.</li> </ul> <p><b>Cough</b></p> <ul style="list-style-type: none"> <li>■ Assessment for persistent cough is similar to that described for breathlessness. The date of onset and characteristics of the cough should be confirmed. For most people, persistent cough is dry, irritating and non-productive, but if sputum is present, this should be further investigated.</li> <li>■ The following assessments may be indicated for persistent cough: <ul style="list-style-type: none"> <li>○ Spirometry – pre- and post-bronchodilator</li> <li>○ Fractional exhaled nitric oxide</li> <li>○ DLCO</li> <li>○ CXR</li> </ul> </li> </ul> <p><b>Depression and anxiety</b></p> <ul style="list-style-type: none"> <li>■ Validated scales may be used for assessment of symptoms of depression and anxiety. It is important to note that these are screening tools and should not be used on their own to make a diagnosis of clinical depression or assess severity; <ul style="list-style-type: none"> <li>○ Patient Health Questionnaire</li> <li>○ Quality of Life in Neurological Disorders</li> <li>○ Depression, Anxiety and Stress Scale</li> <li>○ Hospital Anxiety and Depression Scale</li> <li>○ Somatic and Psychological Health Report</li> </ul> </li> </ul> |
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|  | <p><b>PTSD</b></p> <ul style="list-style-type: none"> <li>▪ There are 2 distinct diagnostic systems with differing criteria for PTSD: <ul style="list-style-type: none"> <li>○ The Diagnostic and Statistical Manual of Mental Disorders, 5<sup>th</sup> edition– includes 20 different symptoms across the domains of re-experiencing, avoidance, negative cognitions and moods and hyperarousal</li> <li>○ The International Classification of Diseases, 11th revision– includes 6 symptoms across 3 domains: re-experiencing, avoidance and hyperarousal</li> </ul> </li> </ul> <p><b>Cognitive impairment ('brain fog')</b></p> <ul style="list-style-type: none"> <li>▪ There are a number of validated screening tools to assess for cognitive impairment, including: <ul style="list-style-type: none"> <li>○ Mini-Mental State Examination</li> <li>○ Montreal Cognitive Assessment</li> <li>○ Rowland Universal Dementia Assessment Scale – for people from culturally and linguistically diverse backgrounds</li> <li>○ Kimberley Indigenous Cognitive Assessment– for Aboriginal and Torres Strait Islander people, particularly those living in rural and remote areas of Australia</li> <li>○ General Practitioner Assessment of Cognition</li> </ul> </li> <li>▪ One of the limitations of these tools is that they are designed for use with older people, particularly those with symptoms of dementia, and may have limited sensitivity for cognitive decline in younger populations.</li> <li>▪ Tools that may be more suitable for younger people with cognitive symptoms include: <ul style="list-style-type: none"> <li>○ Number span forward (attention) and backway (working memory)</li> <li>○ Trail Making Test Part A and B (processing speed and executive functioning)</li> <li>○ Hopkins Verbal Learning Test Revised</li> </ul> </li> <li>▪ It is important to note that cognitive impairment may be secondary to other PASC such as depression and hence, a holistic health assessment is required. Assessment of cognitive impairment should be followed up by assessment of functional outcomes and quality of life to ascertain the impact on a person's activities of daily living. Suitable tools include: <ul style="list-style-type: none"> <li>○ EQ-5D-5L</li> <li>○ Barthel Index</li> <li>○ 12 item Short Form Survey</li> <li>○ PROMIS-29</li> </ul> </li> </ul> <p><b>Joint and Muscle Pain</b></p> <ul style="list-style-type: none"> <li>▪ A full patient history should be undertaken, each involved joint inspected and palpated, and range of motion estimated. The presence of tenderness, warmth or swelling should be investigated. Movements, time of day or activities that exacerbate symptoms should be noted.</li> <li>▪ A medication history should be obtained. The clinician should explore if the person gains relief from over-the-counter medication such as anti-inflammatory agents, topical treatments, heat or ice.</li> </ul> |
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|  | <ul style="list-style-type: none"> <li>▪ Blood tests and imaging may be required based on history and examination findings. For those with a history of rheumatoid arthritis or new onset polyarthropathy, testing of antibodies and rheumatoid factors may be warranted, with referral to a rheumatologist where indicated.</li> </ul> <p><b>Functional Mobility impairment</b></p> <ul style="list-style-type: none"> <li>▪ Consistent with the International Classification of Functioning, Disability and Health definition, people should be asked to report changes in their mobility in 3 domains: <ul style="list-style-type: none"> <li>○ Ability to move around their home, e.g. standing up after sitting in a chair</li> <li>○ Ability to engage in housework</li> <li>○ Ability to engage in physical activity, e.g. walking up a flight of stairs without assistance</li> </ul> </li> <li>▪ For people aged 65 years or older, the Physical Activity Scale for the Elderly may be used to assess information on leisure, household and occupational activity.</li> <li>▪ Referral to physiotherapy and/or occupational therapy for further assessment.</li> <li>▪ Referral to a physiotherapist may be indicated for further assessments including: <ul style="list-style-type: none"> <li>6-minute walk test</li> <li>Dive repetition sit to stand or one minute sit to stand</li> <li>Berg balance scale</li> <li>Timed up and go test</li> <li>Barthel index</li> <li>Functional independence measure</li> </ul> </li> <li>▪ Assessment by an occupational therapist will include assessment of both physical function and home environment. This is particularly important if concerns for safety of the person in their own home are present.</li> </ul> <p><b>Palpitations and chest pain</b></p> <ul style="list-style-type: none"> <li>▪ Ischaemic heart disease, ischaemic cardiomyopathy and arrhythmia may all contribute to or cause exertional dyspnoea. Consider these diagnoses, especially in those with a history of heart disease or risk factors for ischaemic heart disease.</li> <li>▪ Evaluation of new onset chest pain should be performed in an emergency department using the NSW Health Guideline Pathway for Acute Coronary Syndrome. This pathway recommends the use of serial ECG and troponin testing to risk stratify patients into groups requiring invasive angiography or suitable for non-invasive testing with exercise stress testing, CT coronary angiography or stress echocardiography depending on local availability and patient factors.</li> <li>▪ Further evaluation of chest pain should include echocardiography to investigate left ventricular function, exclude regional wall motion abnormalities and exclude the presence of pericardial effusions.</li> <li>▪ Further evaluation of palpitations can include echocardiography, ambulatory ECG monitoring and dynamic evaluation of heart rate and blood pressure (e.g. lying and standing or tilt testing). A definite diagnosis of POTS syndrome should be made at a centre familiar with this condition.</li> </ul> |
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|   | <p><b><i>Gustatory and/or olfactory dysfunction</i></b></p> <ul style="list-style-type: none"> <li>▪ The clinician should perform a full comprehensive examination to rule out any other causes for the person's symptoms, such as nasal polyps, dental problems or cigarette smoking.</li> <li>▪ Certain medications can also cause altered sense of taste or smell. Referral to an ear, nose and throat specialist for in-depth assessment may be indicated.</li> <li>▪ There is no specific diagnostic test to assess altered senses of smell or taste. The experience is subjective and hence, the clinician must rely on the person's self-reported experience. There are several ways to measure symptoms more objectively such as: <ul style="list-style-type: none"> <li>○ Olfactory psychophysical assessment tools, such as odour thresholds (measuring the lowest strength of a chemical that you can recognise), odour discrimination (differentiation between different odours) and odour identification (identification of odours).</li> <li>○ Comparing tastes and smells of different chemicals.</li> <li>○ Scratch and sniff tests.</li> <li>○ Sip, spit and rinse tests where chemicals are placed on certain parts of the tongue.</li> </ul> </li> </ul>   |
| <b>Management and treatment</b>   |   |
| <p><b>Recommendations for treatment and or management of long COVID</b></p> | <p><b>Recommendations relating to management: specific symptoms</b></p> <p><b><i>Fatigue</i></b></p> <ul style="list-style-type: none"> <li>▪ Provide patient education, particularly on the pattern and behaviour of the disease (and its recovery) to set realistic goals and timelines for return to baseline function. The concept of post-exertional malaise should be explained carefully to patients to prevent over-exertion.</li> <li>▪ Treat any underlying or comorbid conditions that may enhance symptoms of fatigue, e.g. depression. This should include an exploration of the person's interpersonal context.</li> <li>▪ People experiencing fatigue and deconditioning after a long hospital stay will benefit from a supervised rehabilitation program and should be referred to local rehabilitation services. A multidisciplinary rehabilitation team will include a rehabilitation physician, allied health clinicians (including physiotherapy, occupational therapy, social work, psychology, speech pathology, dietetics as required) and nurses. Older people may benefit from review in multidisciplinary geriatric medicine clinics.</li> <li>▪ Support patients in discussions with their employer or educational institutions about a phased return to work or education</li> <li>▪ Assist patient to set a baseline for activities that do not exacerbate symptoms and energy conservation and pacing strategies. A graded return to activity is recommended, however this should be self-paced rather than imposed by the clinician to prevent post-exertion malaise. Referral to a clinician with expertise in pacing strategies, such as an occupational therapist, pulmonary rehabilitation physiotherapist or psychologist, may be appropriate.</li> <li>▪ Provide advice for improving quality of rest, sleep hygiene and nutrition to help improve energy levels.</li> </ul> <p><b><i>Breathlessness</i></b></p> |

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|  | <ul style="list-style-type: none"> <li>▪ Consider referral to respiratory medicine for all people with moderate to severe breathlessness that is limiting exercise tolerance and persistent for greater than 4 weeks following acute COVID 19 diagnosis. The referring clinician should perform appropriate initial investigations before referral (including spirometry, DLCO and a CXR).</li> <li>▪ A high-resolution CT scan of the chest should not be the first screening test to assess persistent breathlessness.</li> <li>▪ Referrals to pulmonary rehabilitation where there is evidence of physiological pulmonary impairment and reduced exercise tolerance, especially in those that have been hospitalised for acute COVID-19, pulmonary rehabilitation has been shown to result in an improvement in exercise tolerance, health-related quality of life and symptoms.</li> <li>▪ Following assessment at pulmonary rehabilitation and consultation with the person, an appropriate model of rehabilitation can be offered, e.g. gym-based, home-based or tele-rehabilitation, or hydrotherapy.</li> <li>▪ Pulmonary rehabilitation offers: <ul style="list-style-type: none"> <li>○ Individualised exercise assessment, prescription, supervised exercise training and advice on the gradual return to exercise and physical activity</li> <li>○ Education and techniques to manage breathlessness, such as paced breathing and breathing control. Education may also include management of fatigue, including post-exertional malaise, importance of exercise and physical activity, symptom management and monitoring, inhaler medication education (where applicable), smoking cessation, nutrition, psychological support, and managing cough and sputum</li> </ul> </li> <li>▪ Refer all people with moderate to severe persistent breathlessness, especially those with evidence of impaired lung function and exercise tolerance, and those with pre-existing chronic lung disease to the local pulmonary rehabilitation program.</li> <li>▪ Refer people with mild impairment in exercise tolerance to a community physiotherapist or exercise physiologist under a chronic disease management plan.</li> </ul> <p><b>Cough</b></p> <ul style="list-style-type: none"> <li>▪ The management of persistent cough will depend on assessment findings, particularly the presence of any pulmonary abnormalities. In the absence of any specific pulmonary findings, persistent cough is managed in a similar fashion to cough in patients with post-viral cough syndrome</li> <li>▪ Refer people with persistent severe cough to a respiratory physician for further assessment and management.</li> <li>▪ Referrals to community physiotherapy or pulmonary rehabilitation. If a person is having ongoing issues with sputum production, refer to a physiotherapist with expertise in airway clearance. Their advice and technique may be beneficial. Further investigations for bronchiectasis may be indicated.</li> </ul> <p><b>Depression and anxiety</b></p> <ul style="list-style-type: none"> <li>▪ Treatment should be based on the severity of presenting symptoms.</li> </ul> |
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|  | <ul style="list-style-type: none"> <li>■ Management of symptoms may include referral to specialist services and pharmacological interventions, such as antidepressants or benzodiazepines.</li> <li>■ Referral to psychology for those with commonly reported mental health symptoms, such as symptoms of mild anxiety or depression, supportive counselling and close follow-up by the person's GP is indicated. Referral to a psychologist by the person's GP may also be required.</li> <li>■ Referral to psychiatric services for those with more complex needs, referral to a consultation liaison psychiatry service or private psychiatrist may be indicated.</li> </ul> <p><b>PTSD</b></p> <ul style="list-style-type: none"> <li>■ Some people experiencing PTSD may be adequately managed by their GP.</li> <li>■ Other people may benefit from referral to a clinical psychologist for specific trauma related therapy such as trauma-focused cognitive behaviour therapy, eye movement desensitisation and reprocessing, imagery rehearsal therapy or equine therapy.</li> <li>■ Referral to a psychiatrist may be indicated in cases of severe, persisting symptoms impacting on functioning or where more complex pharmacotherapy advice is required.</li> </ul> <p><b>Cognitive impairment ('brain fog')</b></p> <ul style="list-style-type: none"> <li>■ The following interventions have been shown to demonstrate improvement in symptoms of cognitive impairment: <ul style="list-style-type: none"> <li>○ Physiotherapist designed or supervised individualised activity and movement program. Cautious clinical judgment should be used in recommending exercise to people with significant fatigue due to the risk of post-exertional malaise.</li> <li>○ A full medication review by a GP or rehabilitation physician, as some medications may exacerbate symptoms. For a person aged over 65, a geriatrician should be consulted.</li> <li>○ Improved sleep hygiene.</li> <li>○ Improved nutrition.</li> <li>○ Neuropsychological rehabilitation strategies, usually performed by a neuropsychologist or multidisciplinary rehabilitation service. The strategies may include neuroplasticity-based therapies such as cognitive mapping, errorless learning and repetition of information.</li> </ul> </li> </ul> <p><b>Joint and Muscle pain</b></p> <ul style="list-style-type: none"> <li>■ In most instances, joint and/or muscle pain post COVID-19 illness will resolve within 2-3 months.</li> <li>■ Conservative management is usually adequate. Analgesia such as paracetamol or anti-inflammatories, such as ibuprofen, may be recommended. The use of heat packs may also provide relief.</li> <li>■ A physiotherapy assessment should be sought for individualised activity or movement prescription, particularly in the event of restricted range of motion or weakness.</li> <li>■ Cautious clinical judgment should be used in recommending exercise to people with significant fatigue due to the risk of post-exertional malaise.</li> </ul> |
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|  | <ul style="list-style-type: none"> <li>▪ If pain continues, referral to a rehabilitation medicine specialist, rheumatologist or pain specialist may be indicated.</li> </ul> <p><b>Functional Mobility impairment</b></p> <ul style="list-style-type: none"> <li>▪ Referral to a rehabilitation physician for a comprehensive multidisciplinary rehabilitation assessment and intervention is recommended. Multidisciplinary rehabilitation may be delivered in an inpatient, day program or outpatient modality depending on symptom burden. This rehabilitation program may involve interventions including; <ul style="list-style-type: none"> <li>○ Falls prevention</li> <li>○ Muscle strengthening</li> <li>○ Balance training</li> <li>○ Training for activities of daily living (e.g. cooking)</li> <li>○ Home assessment</li> <li>○ Cognitive mapping</li> </ul> </li> <li>▪ In mild to moderate cases of reduced mobility, referral to an outpatient or community physiotherapist and/or occupational therapist is appropriate. Exercise prescription and education can be provided to improve functional abilities, pacing and energy conservation. Adding in a social element via a group program, such as a falls prevention or exercise group, may improve adherence and motivation. Technology may be used to support self-directed exercise programs. Assessment of the safety of the home environment by an occupational therapist may include recommendations for home modifications or assistive technology where required.</li> </ul> <p><b>Palpitations and chest pain</b></p> <ul style="list-style-type: none"> <li>▪ Management of chest pain post COVID-19 is dependent on the aetiology identified using the Pathway for Acute Coronary Syndrome evaluation following the Heart Foundation Acute Coronary Syndrome clinical guidelines.</li> <li>▪ In the majority of cases, no concerning aetiology is identified, and the management is supportive. If post-COVID-19 pericarditis and myocarditis is identified, then serial clinical and echocardiographic review is warranted.</li> <li>▪ Management of post-COVID-19 POTS is complex. Referral to a specialist with experience in managing POTS is recommended.</li> </ul> <p><b>Gustatory and/or olfactory dysfunction</b></p> <ul style="list-style-type: none"> <li>▪ Olfactory training involves the person exposing themselves to 4 different odours twice daily for at least 24 weeks. The different scents are typically phenylethyl alcohol (rose scent), eucalyptol (eucalyptus scent), citronella (lemon scent), and eugenol (clove scent).</li> </ul> |
| <b>Service planning</b>                                    |   |
| <b>Recommendations for service planning for long COVID</b> | <p><b>Recommended services and clinicians for the establishment of a dedicated PASC clinic:</b></p> <ul style="list-style-type: none"> <li>▪ Respiratory physician</li> </ul>   |

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|  | <ul style="list-style-type: none"> <li>▪ Rehabilitation physician</li> <li>▪ Pulmonary rehabilitation service</li> <li>▪ Geriatric medicine</li> <li>▪ An allied health practitioner or nurse to act in a coordinator and patient education function</li> <li>▪ Allied health practitioners including physiotherapy, occupational therapy, speech pathology, clinical psychology, neuropsychology, dietetics, exercise physiology and social work</li> <li>▪ Access to interpreter services</li> <li>▪ Access to Aboriginal health services</li> <li>▪ Other medical specialties, which may be required depending on patient symptoms, include but are not limited to, cardiology, infectious diseases, rheumatology, haematology, psychiatry, drug and alcohol services, endocrinology and renal medicine.</li> </ul> |
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**Key:** CXR - chest X-ray; CT - computed tomography; DLCO - diffusing capacity for carbon monoxide is a measurement of gas factor transfer; ECG - electrocardiogram; ICU - intensive care unit; NSW - New South Wales; PASC - post-acute sequelae of COVID-19; POTS- postural orthostatic tachycardia syndrome; PROMIS-29 - patient-reported outcomes measurement information system; PTSD – post traumatic stress disorder; WHO – World Health Organization.

\* COVID-19 Yorkshire rehabilitation scale screens for the most common symptoms of post-acute Sequelae of SARS-CoV-2 and grades the severity of symptoms to provide a score of burden, functional disability, and global health. These scores provide the clinician information on the most burdensome of symptoms so that they can focus on what matters most to the patient. They also provide a reference point which allows the patient to focus on self-reported symptoms and demonstrate progress



### Appendix 3.17 Data extraction table for Clinical management of COVID-19 patients: living guideline - Rehabilitation of adults with post COVID-19 condition

| Clinical guideline and or model of care characteristics  |  |
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| <b>Endorsing Organisation</b>  | World Health Organisation (WHO)  |
| <b>Title</b>   | Clinical management of COVID-19 patients: living guideline - Rehabilitation of adults with post COVID-19 condition   |
| <b>Country</b>   | International  |
| <b>Date Published</b>  | 15 September 2022 (for v5.0 – post COVID-19 condition)   |
| <b>URL</b>   | <a href="https://covid19.who.int/">https://covid19.who.int/</a><br><a href="https://WHO/2019-nCoV/Post_COVID-19_condition/Clinical_case_definition/2021.1">https://WHO/2019-nCoV/Post_COVID-19_condition/Clinical_case_definition/2021.1</a><br><a href="https://www.who.int/publications/i/item/WHO-2019-nCoV-Clinical-2022.2">https://www.who.int/publications/i/item/WHO-2019-nCoV-Clinical-2022.2</a>  |
| <b>National or regional</b>  | International  |
| <b>Adapted from previous guidelines and or model of care?<br/>If so which guidelines and or model of care was it adapted from?</b> | N/A  |
| <b>Update(s) planned (including dates)</b>   | Living guideline: The stated aim is to produce at least 2 updates per year.  |
| Definition and diagnosis   |  |
| <b>Definition of long COVID used in the guideline and or model of care</b>   | <p><b>Post COVID-19 condition</b></p> <ul style="list-style-type: none"> <li>Occurs in individuals with a history of probable or confirmed SARS-CoV-2 infection, usually 3 months from the onset of COVID-19 with symptoms that last for at least 2 months and cannot be explained by an alternative diagnosis. Symptoms may be new onset following initial recovery from an acute COVID-19 episode, or persist from the initial illness period (<a href="#">WHO clinical case definition</a>). Symptoms and impairments can present as either clusters or isolated symptoms that limit daily activities and restrict social participation. Symptoms may be present for prolonged time frames and/or relapse over time.</li> </ul> |
| <b>Recommendations for diagnosis of long COVID</b>   | Nothing other than a service planning recommendation: Standardised symptoms assessment and outcome measurement (already captured in the service planning box below).   |
| Management and treatment   |  |
| <b>Recommendations for treatment and or management of long COVID</b>   | <p><b>Strong Recommendations</b></p> <ul style="list-style-type: none"> <li>In adults with post COVID-19 condition exertional desaturation and cardiac impairment following COVID-19 should be ruled out and managed before consideration of physical exercise training. While orthostatic intolerance and PESE are amenable to rehabilitation, their presence will require interventions to be modified in view of these diagnoses for rehabilitation to be safe.</li> </ul>  |

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|  | <p><b>Conditional Recommendations</b></p> <ul style="list-style-type: none"> <li>▪ An early referral of adults with post COVID-19 condition for appropriate rehabilitation services is suggested when experiencing symptoms and impairments that may be managed effectively and that have an impact on everyday functioning, when red flags for safe rehabilitation have been considered.</li> <li>▪ For the clinical rehabilitation management of PESE in adults with post COVID-19 condition we suggest using education and skills training on energy conservation techniques such as pacing approaches. The provision and training in the use of assistive products and environmental modifications may be useful for people experiencing moderate to severe PESE.</li> <li>▪ For the clinical rehabilitation management of arthralgia in adults with post COVID-19 condition we suggest using a combination of pain education, skills training on self-management strategies, prescription of short-term anti-inflammatory drugs, and in the absence of PESE physical exercise training.</li> <li>▪ For the clinical rehabilitation management of breathing impairment in adults with post COVID-19 condition we suggest using a combination of education and skills training on self-management strategies such as nasal breathing and pacing approaches and, in the absence of PESE, physical exercise training. Breathing control techniques could be offered to those presenting with a suboptimal breathing pattern, and psychological support may be useful to address contributing factors such as anxiety.</li> <li>▪ For the clinical rehabilitation management of cognitive impairment in adults with post COVID-19 condition we suggest using a combination of education, skills training on self-management strategies and cognitive exercises. The provision and training in the use of assistive products and environmental modifications may be useful to address the cognitive dysfunctions as they apply to daily functioning.</li> <li>▪ For the clinical rehabilitation management of fatigue in adults with post COVID-19 condition we suggest using a combination of education, skills training on energy conservation techniques such as pacing approaches and, in the absence of PESE, a cautious return to symptom titrated physical exercise training. The provision and training in the use of assistive products and environmental modifications may be considered for people experiencing levels of fatigue that limit instrumental activities of daily living. Psychological support may be offered to support coping with the symptom.</li> <li>▪ For the clinical rehabilitation management of anxiety and depression in adults with post COVID-19 condition we suggest using psychological support and, in the absence of PESE, physical exercise training. In addition, mindfulness-based approaches and peer support groups may be useful to reduce distress in some people with post COVID-19 condition when managing long-term symptoms.</li> <li>▪ For the clinical rehabilitation management of olfactory impairment in adults with post COVID-19 condition we suggest using education and skills training for olfactory training.</li> <li>▪ For the clinical rehabilitation management of orthostatic intolerance in adults with post COVID-19 condition we suggest using a combination of education and skills training on self-management strategies and, in the absence of PESE, physical exercise training. Environmental modifications may be useful to support activities of daily living for people experiencing difficulties with upright positions or standing.</li> </ul> |
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|   | <ul style="list-style-type: none"> <li>▪ For the clinical rehabilitation management of swallowing impairment in adults with post COVID-19 condition we suggest using a combination of education and skills training on positioning, manoeuvres and dietary modifications, and swallowing exercises.</li> <li>▪ For the clinical rehabilitation management of voice impairment in adults with post COVID-19 condition we suggest using education and skills training about voice rest and vocal behaviours. In addition, any combination of respiratory exercises and vocal training may be considered.</li> <li>▪ Interventions for rehabilitation for a return to everyday activities in post COVID-19 condition could include education and skills training on energy conservation techniques, and the provision and training in the use of assistive products to those who need further assistance with activity management and mobility. For a return to work we suggest using a return to work action plan with a prolonged and flexible phased return. Environmental modifications at work may be needed based on an individualized workplace risk assessment of personal capabilities matched to work requirements.</li> </ul>   |
| <b>Service planning</b>   |   |
| <p><b>Recommendations for service planning for long COVID</b></p> | <p><b>Conditional Recommendations</b></p> <ul style="list-style-type: none"> <li>▪ To support the delivery of rehabilitation services for post COVID-19 condition we suggest the following core components: 1. Multidisciplinary rehabilitation teams; 2. Continuity and coordination of care; and 3. People-centred care and shared decision-making.</li> <li>▪ To support the operationalization of the core components, planners could implement core functions, including: 1. Standardised symptoms assessment and outcome measurement; 2. Follow-up system; and 3. Referral system.</li> <li>▪ For rehabilitation service delivery for post COVID-19 condition we suggest using a hybrid approach of in-person and remote models that is integrated across all levels of healthcare. It is suggested that the length of a rehabilitation programme is based on patient needs, enabling re-engagement if new onset functional decline occurs.</li> <li>▪ A workforce for the rehabilitation of adults with post COVID-19 condition may include but is not limited to physiotherapists, occupational therapists, nurses, psychologists, speech and language therapists, physicians and social workers. Community healthcare workers may be required based on local needs.</li> </ul> |

**Key:** N/A - not applicable; PESE - post-exertional symptom exacerbation.

### Appendix 3.18 Data extraction table for Clinical rehabilitation guideline for people with long COVID (coronavirus disease) in Aotearoa New Zealand

| Clinical guideline and or model of care characteristics  |   |
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| <b>Endorsing Organisation</b>  | Ministry of Health  |
| <b>Title</b>   | Clinical rehabilitation guideline for people with long COVID (coronavirus disease) in Aotearoa New Zealand  |
| <b>Country</b>   | New Zealand   |
| <b>Date Published</b>  | 16 September 2022   |
| <b>URL</b>   | <a href="https://www.health.govt.nz/system/files/documents/publications/clinical-rehabilitation-guideline-for-people-with-long-covid-sep22.pdf">https://www.health.govt.nz/system/files/documents/publications/clinical-rehabilitation-guideline-for-people-with-long-covid-sep22.pdf</a>   |
| <b>National or regional</b>  | National  |
| <b>Adapted from previous guidelines and or model of care?<br/>If so which guidelines and or model of care was it adapted from?</b> | No.<br>Relied on a consensus statement from NICE, and a panel of UK primary and secondary care practitioners.   |
| <b>Update(s) planned (including dates)</b>   | The guidelines will be updated as new evidence relevant to the Aotearoa New Zealand population and situation, becomes available but no dates reported.  |
| Definition and diagnosis   |   |
| <b>Definition of long COVID used in the guideline and or model of care</b>   | <b>Post-COVID-19 syndrome (long COVID)</b> <ul style="list-style-type: none"> <li>Signs and symptoms, consistent with COVID-19, that develop during or after an infection, continues for more than 12 weeks and are not explained by an alternative diagnosis. (<i>Adapted from NICE clinical case definition</i>)</li> </ul>   |
| <b>Recommendations for diagnosis of long COVID</b>   | <b>Recommendations (Grade B: Fair evidence)</b> <ul style="list-style-type: none"> <li>All health clinicians should consider long COVID in anyone with a wide range of presenting features (not limited to fatigue and breathlessness) occurring 12 weeks or more after a confirmed or probable infection with COVID-19 in their differential diagnosis where appropriate.</li> </ul> <b>Indications for further investigation and specific therapies for: (Grade B: Fair evidence)</b> <ul style="list-style-type: none"> <li>Myocarditis</li> <li>MIS-C or PIMS-Ts</li> <li>PoTS</li> <li>Mast cell activation syndrome (blood disorder)</li> <li>Hypoxia/desaturation</li> <li>Chest pain</li> <li>Palpitations</li> </ul> |

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|  | <ul style="list-style-type: none"> <li>▪ Histamine intolerance symptoms.</li> </ul> <p><b>Good Practice Point (Grade C: Expert opinion)</b><br/> <b><i>Consider the following red flags for patients presenting with ongoing symptoms from COVID-19, these should be managed when identified from clinical assessment:</i></b></p> <ul style="list-style-type: none"> <li>▪ Heart failure</li> <li>▪ Pulmonary embolism</li> <li>▪ Acute coronary syndrome</li> <li>▪ PESE</li> <li>▪ Myocarditis</li> <li>▪ Chest pain</li> <li>▪ Tightness, worsening or increasing palpitations, dyspnoea, desaturation in exertion</li> <li>▪ PoTS</li> <li>▪ Coagulation dysfunction</li> <li>▪ FND</li> </ul> <p>Children and Young people</p> <ul style="list-style-type: none"> <li>▪ Pulmonary embolism</li> <li>▪ Myocarditis</li> <li>▪ Cardiomyopathy</li> <li>▪ Venous thromboembolism</li> <li>▪ Renal failure</li> <li>▪ Type 1 Diabetes mellitus</li> <li>▪ PIMS-Ts</li> <li>▪ MIS-C</li> <li>▪ FND</li> <li>▪ Paediatric Acute-onset Neuropsychiatric Syndrome</li> </ul> <p><b><i>Consider the following yellow flags for patients with ongoing symptoms from COVID-19:</i></b></p> <ul style="list-style-type: none"> <li>▪ Elevated heart rate</li> <li>▪ Increased oxygen demand</li> <li>▪ Orthostatic hypotension</li> <li>▪ Pre-existing conditions and or psychological and or psychosocial factors that could predict poor outcome</li> </ul> <p>Children and Young People</p> <ul style="list-style-type: none"> <li>▪ Absenteeism from school / education</li> </ul> <p><b>Recommendations</b></p> <ul style="list-style-type: none"> <li>▪ Long COVID appears to be more common among people who have severe COVID-19 symptoms during acute illness, but it can also affect those who initially had mild or moderate COVID-19. There appears to be</li> </ul> |
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|  | <p>no specific time course, symptoms may improve one week and relapse the next. The expected time to recovery from symptoms of COVID-19 are: (Grade B: Fair evidence)</p> <ul style="list-style-type: none"> <li>○ 4 weeks for muscle aches, chest pain, and sputum production.</li> <li>○ 6 weeks for cough and breathlessness to be significantly improved, if not fully resolved.</li> <li>○ 3 months for most other symptoms with residual fatigue.</li> <li>○ 6 months for all symptoms unless the patient had a complicated/prolonged admission to intensive care.</li> </ul> <ul style="list-style-type: none"> <li>■ There are many similarities between post-COVID-19 conditions, other post-infectious fatigue syndromes, and ME/CFS. There is no current consensus as to whether ME/CFS can result from COVID-19. (Grade C: Expert opinion)</li> <li>■ Presentations in the post-acute COVID-19 scenario are likely to be for: (Grade C: Expert opinion) <ul style="list-style-type: none"> <li>○ Nonspecific post viral symptoms, particularly fatigue, breathlessness chest pain and palpitations.</li> <li>○ Specific serious sequelae resulting from the acute infection, or as delayed complications.</li> <li>○ Recovery after severe illness that required intensive care management.</li> <li>○ Psychosocial effects of prolonged symptoms and functional impairment.</li> </ul> </li> </ul> <p><b>Frequently reported symptoms include:</b> (<i>Appears to be ungraded</i>)</p> <ul style="list-style-type: none"> <li>■ Anxiety</li> <li>■ Depression</li> <li>■ Fatigue</li> <li>■ Breathlessness, cough and abnormal breathing patterns</li> <li>■ Brain fog</li> <li>■ Cognitive changes including memory impairment</li> <li>■ Sleep disturbances</li> <li>■ Exercise intolerance, not returning to usual level of exercise</li> <li>■ PEM</li> <li>■ PESE</li> <li>■ Post intensive care syndrome</li> <li>■ Orthostatic intolerance, dysautonomia and PoTS</li> <li>■ Communication, speech, voice and swallowing difficulties</li> <li>■ Changes in eating patterns and appetite</li> <li>■ Changes in bowel habits</li> <li>■ Headache</li> <li>■ Loss of taste and smell</li> <li>■ Muscle weakness</li> <li>■ Muscle/joint pain</li> </ul> |
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| <b>Management and treatment</b>                                      |   |
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| <b>Recommendations for treatment and or management of long COVID</b> | <p><b>Recommendations (The impact of Vaccination after infection on long COVID)</b></p> <ul style="list-style-type: none"> <li>▪ Vaccination should start or continue after 3 months following COVID-19 (Grade B: Fair evidence)</li> </ul> <p>Practice Point</p> <ul style="list-style-type: none"> <li>▪ Clinicians should work with whānau to start or continue vaccination 3 months from diagnosis with the acute illness (Grade C: Expert opinion)</li> </ul> <p><b>Recommendations (Pharmacology)</b></p> <ul style="list-style-type: none"> <li>▪ Medications for long COVID are not yet validated (Grade B: Fair evidence)</li> </ul> <p>Practice Point</p> <ul style="list-style-type: none"> <li>▪ Medications for specific symptom management may be of benefit e.g. sleep disturbance, or to support mental health and wellbeing (Grade C: Expert opinion)</li> </ul> <p><b>Key recommendations for symptom management</b></p> <ul style="list-style-type: none"> <li>▪ Rehabilitation should be tailored/appropriate for individuals and their whānau, with careful activity pacing, to avoid relapse, and with transdisciplinary support. (Grade A: Good evidence)</li> </ul> <p><b>Issues with Mental Health and wellbeing:</b></p> <ul style="list-style-type: none"> <li>▪ For individuals who are experiencing anxiety, or depression, by not acknowledging the condition can exacerbate the high level of distress some individuals are already experiencing. Anxious feelings, and stress are normal, reassurance of these normal emotions is important. Options for support include GP team and supportive friends. (Grade B: Fair evidence)</li> <li>▪ Individuals are likely to need support with BOTH the process (expectations, adjustment, navigating services) and the outcomes (managing symptoms of distress). (Appears to be ungraded)</li> <li>▪ Individuals need access to timely, good quality information and well-informed Multi-disciplinary team support to help them (and others) form realistic expectations of their recovery, as well as to help manage their symptoms. (Appears to be ungraded)</li> <li>▪ Experience suggests that positive contact with others who are experiencing similar issues is extremely helpful for that process- making coordinated group- and peer-based approaches of particular benefit. (Appears to be ungraded)</li> <li>▪ 'The process' may not be the same for all individuals. Particular consideration needs to be given to support Māori individuals and whānau, as well as disabled people.</li> <li>▪ There is strong research evidence for individual and group-based programmes to help individuals manage many of the commonly reported issues. (Appears to be ungraded)</li> <li>▪ Given the high number of individuals experiencing symptoms of trauma/PTSD, suicidal ideation, and cognitive difficulties, many may need to be supported to access more intensive (neurological) psychological interventions. (Appears to be ungraded)</li> </ul> <p><b>Fatigue:</b></p> |

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|  | <ul style="list-style-type: none"> <li>■ Customised information and resources about fatigue management and pacing activities such as the use of the 'energy envelope' should be made available for individuals and their whānau. These strategies need to be tailored for the lifestyle, culture, environment, and social demands in the person's life and that of their whanau (Grade C: Expert opinion)</li> <li>■ Referral to an occupational therapist for assessment and treatment may be of benefit for individuals who require additional support for management of this symptom. Occupational therapists work in private and public health services and can be accessed by referring to local Te Whatu Ora districts via local pathways or making contact with private organisation directly. (Grade C: Expert opinion)</li> <li>■ Customised supports to meet needs of disabled people or those with existing health conditions to manage additional impacts on their health and wellbeing. (Appears to be ungraded)</li> <li>■ Equipment or adaptive aids can assist individuals who need these for rehabilitation or due to fatigue. (Appears to be ungraded)</li> </ul> <p><b>Breathing pattern disorder, cough, reduced exercise tolerance or muscle weakness:</b></p> <ul style="list-style-type: none"> <li>■ Individuals presenting with breathing pattern disorder, cough, reduced exercise tolerance that isn't improving or symptoms getting worse after graded exercise, or muscle weakness following COVID-19 infection are likely to benefit from a referral to a physiotherapist and/or speech-language therapist with skills in managing breathing pattern disorder for assessment and treatment. Referrals can be made through to local Te Whatu Ora districts via local pathways or by contacting a physiotherapist or speech-language therapist directly. (Grade B: Fair evidence)</li> <li>■ Reduced exercise tolerance, caused by altered ventilation and circulation and not deconditioning. (Appears to be ungraded)</li> <li>■ Individuals who experience a worsening of symptoms following exercise should seek advice from their family doctor or a physiotherapist. Clinicians are to prescribe graded exercise therapy after a thorough assessment of the absence of PEM/PESE. It is essential to assess for the following: (Appears to be ungraded) <ul style="list-style-type: none"> <li>○ Cardiac symptoms; breathless on exertion, tachycardia, chest pain</li> <li>○ PESE DePaul PEM Questionnaire is a useful outcome measure.</li> <li>○ Oxygen desaturation on exertion-desaturation of more than 3% needs investigation</li> <li>○ Autonomic dysautonomia- breathlessness, palpitations, fatigue, chest pain, syncope, feeling faint can contribute to exercise intolerance.</li> <li>○ Screen for orthostatic intolerance or PoTs – using NASA lean test or active stand. It is difficult to distinguish from cardiac conditions and therefore requires medical examination.</li> </ul> </li> </ul> <p><b>Cough:</b></p> <ul style="list-style-type: none"> <li>■ Education, cough substitution techniques and reducing airway irritants can support re-education of chronic cough and abnormal breath patterns. Reasons for ongoing cough are likely to benefit from a referral to a physiotherapist and/or speech-language therapist with skills in managing cough. (Appears to be ungraded)</li> <li>■ The Leicester cough questionnaire is mentioned. (Appears to be ungraded)</li> </ul> |
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|  | <p><b>Thought processing, memory and 'brain fog':</b></p> <ul style="list-style-type: none"> <li>▪ Individuals presenting symptoms such as sustained and ongoing brain fog, headaches, memory impairment, or other new cognitive difficulties that are severely impacting on day-to-day functioning may benefit from a referral to an occupational therapist, speech-language therapist, psychologist or other appropriately qualified cognitive rehabilitation specialist. (Grade B: Fair evidence)</li> </ul> <p><b>Sleep Issues:</b></p> <ul style="list-style-type: none"> <li>▪ The quality and quantity of sleep of people with long COVID may benefit from advice from healthcare professionals or traditional/cultural health practitioners who specialise in sleep problems as these can be addressed therapeutically. (Grade B: Fair evidence/Grade C: Expert opinion)</li> <li>▪ Rehabilitation specialists such as occupational therapist, speech Language therapists, dietitians, physiotherapists or local sleep clinics may be appropriate for onward referral for serious issues with sleep. Sleep clinics can be accessed by referring to local Te Whatu Ora districts via local pathways. (Grade B: Fair evidence)</li> </ul> <p><b>Post Exertional Malaise/Post Exertional Symptom Exacerbation:</b></p> <ul style="list-style-type: none"> <li>▪ The condition can be triggered by cognitive, physical, mental, or emotional reasons, with onset immediately or 24-72 hours post exertion. (Grade B: Fair evidence)</li> <li>▪ Individuals who experience a worsening of symptoms following exercise should seek advice from their family doctor a physiotherapist or occupational therapist. (Appears to be ungraded)</li> <li>▪ Referral to physiotherapists or occupational therapists may be of benefit for individuals who require additional support for management of this symptom. Physiotherapists and occupational therapists work in private and public health services and can be accessed by referring to local Te Whatu Ora districts via local pathways or making contact with private organisations directly. (Appears to be ungraded)</li> <li>▪ Equipment or adaptive aids can assist individuals who need these for rehabilitation (Appears to be ungraded)</li> <li>▪ Heart rate monitoring can be useful for both predicting a harder day and keeping activities below the ventilatory threshold. Heart rate monitoring can help management/pacing, although there are mixed opinions and suggest using if the individual has an understanding/interest. The energy envelope theory is an alternative which can be used. (Appears to be ungraded)</li> <li>▪ <math>(220 - \text{individual age}) \times 0.55 = \text{anaerobic threshold in beats per minute}</math> – Stay below this heart rate (Appears to be ungraded)</li> <li>▪ Or resting heart rate plus 15 beats per minute (more conservative) (Appears to be ungraded)</li> </ul> <p><b>Dysautonomia Orthostatic intolerance and PoTS:</b></p> <ul style="list-style-type: none"> <li>▪ Symptoms which occur on sitting or standing can include feeling dizzy, faint, lightheaded, or nauseated. (Grade B: Fair evidence)</li> <li>▪ Treatment (Appears to be ungraded) <ul style="list-style-type: none"> <li>○ Fluid intake</li> </ul> </li> </ul> |
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|  | <ul style="list-style-type: none"> <li>○ Salt intake</li> <li>○ Contract relax muscle exercises</li> <li>○ Medical grade compression garments</li> </ul> <p><b>Communication, voice or swallowing issues:</b></p> <ul style="list-style-type: none"> <li>■ If a person takes medicines and swallowing affects ability to safely take medicines, a review should be undertaken and changes to medicine forms made as required. A review could be undertaken by a pharmacist and may require changes to medicine regimen by a prescriber. (Grade B: Fair evidence)</li> <li>■ Individuals with increasing communication, voice or swallowing difficulties should be immediately referred to a speech-language therapist for an urgent assessment. This is particularly important if a person is prone to chest infections or has breathing difficulties already. Referrals can be made through to local Te Whatu Ora districts via local pathways or by contacting a Speech Language therapist directly. (Appears to be ungraded)</li> </ul> <p><b>Headache:</b></p> <ul style="list-style-type: none"> <li>■ Headaches are common during viral infections and usually disappear within a few weeks, however, some people continue to experience headaches many weeks or months after a COVID infection. The presence of a headache does not mean that the virus is still present. Many factors other than a viral infection such as diet, fatigue, lack of sleep and stress can contribute to headaches.</li> <li>■ Long COVID headaches may be more frequently experienced by those who have a history of migraines or headaches.</li> </ul> <p><b>Taste or smell issues:</b></p> <ul style="list-style-type: none"> <li>■ For individuals with loss of taste and smell, provide reassurance that this is not an unusual post COVID-19 symptom. There is not a lot of information about how long it takes for COVID-19 patients to get their sense of smell back. Research from other viruses that affect sense of smell shows us that smell usually returns within 2 weeks but can sometimes take longer. Some people who lose their sense of smell can also lose their sense of taste. (Grade B: Fair evidence)</li> <li>■ For individuals with loss of taste and smell who are at risk of malnutrition should be referred to a dietitian for assessment, treatment and prevention of malnutrition. (Appears to be ungraded)</li> <li>■ If there is a difference in an individual's weight and they are finding it hard to maintain weight, patients can follow the healthy eating basics. If weight loss continues, individuals should be referred to a dietitian for assessment, treatment, and prevention of malnutrition. (Appears to be ungraded)</li> </ul> <p><b>Gastrointestinal changes:</b></p> <ul style="list-style-type: none"> <li>■ Individuals presenting with persistent gastrointestinal symptoms (nausea, bloating, pain, diarrhoea) should be referred to a dietician for assessment and treatment. (Grade C: Expert opinion)</li> </ul> <p><b>Muscle/joint pain:</b></p> <ul style="list-style-type: none"> <li>■ For individuals with muscle and or joint pain, provide reassurance that this is not an unusual post-COVID-19 symptom. Encourage gentle, full range of movement exercises. (Grade C: Expert opinion)</li> </ul> <p><b>Living with long COVID</b></p> |
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|                                | <p>Good Practice Point</p> <ul style="list-style-type: none"> <li>▪ It is essential that a coordinated approach to planning and implementing services is person and whānau-centred. Cultural and community providers who may be supporting the whānau already are key partners in integrating care of multiple services. (Grade C: Expert opinion)</li> <li>▪ A coordinated care or action plan for rehabilitation and management of long COVID should be developed with the individual and whānau by a member of the care team whom they trust and are able to have a long-term relationship with. (Grade C: Expert opinion)</li> </ul> <p><b>Support and service needs</b></p> <p>Good Practice Point</p> <ul style="list-style-type: none"> <li>▪ Ensure options of treatment are available to access underserved communities. (Grade B: Fair evidence)</li> <li>▪ Education about long COVID to communities and providers to support acceptance and decrease discrimination. (Grade C: Expert opinion)</li> <li>▪ Provide specialised options for cultural groups in the region and for priority populations such as Māori, Pacifica Peoples, rural and remote communities, disabled people, older people and those living in Aged residential care. (Grade B: Fair evidence)</li> </ul> <p><b>Children and Young People</b></p> <p>Good Practice Point</p> <ul style="list-style-type: none"> <li>▪ Support Caregivers and monitor for caregiver fatigue. (Grade B: Fair evidence)</li> <li>▪ Plan the day and week to balance activity and rest and maintain energy envelope. (Grade B: Fair evidence)</li> <li>▪ Clinicians to screen for cardiac symptoms prior to sport, risk of boom and bust behaviours, provide symptom guided/paced return to sport. (Grade B: Fair evidence)</li> <li>▪ Consider targeted psychological supports particularly for those children who have experienced more boom bust, experience frustrations, and find it harder to pace. (Grade C: Expert opinion)</li> <li>▪ Maintain level of activity before progressing. See Pacing penguins and Cautious Tortoise from Long COVID kids. (Grade B: Fair evidence)</li> <li>▪ Education needs to be able to be delivered in flexible formats. Home based/online/hybrid and paced to progress to classroom attendance. The child can progress to education or other activities when they are able to participate in home activities. Be mindful of the social, emotional, and sensory overload of school classroom/school attendance and factor into energy conservation/energy envelope. Also be mindful of the effect of decreased school attendance on working parents/caregivers around ability to maintain current employment. (Grade B: Fair evidence)</li> <li>▪ Schools need well ventilated classrooms and children may not tolerate mask use. Communication with the Ministry Of Education, Teachers, Board of Trustees re: continuous carbon dioxide monitoring and appropriate ventilation based on this. (Grade B: Fair evidence)</li> </ul> |
| <p><b>Service planning</b></p> |   |

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| <p><b>Recommendations for service planning for long COVID</b></p> | <p><b>Key elements for the care continuum include (Grade B: Fair evidence):</b></p> <ul style="list-style-type: none"> <li>▪ The use of specific symptom screening and assessment tools to systematically identify post-COVID condition symptoms and functional impairments</li> <li>▪ Pathways to determine patients’ rehabilitation trajectory and to guide their transition between care settings</li> <li>▪ Customised and tailored, personalised management and education resources which are accessible for all people, communities, and providers</li> <li>▪ Working with whānau and iwi to develop personalised management and education resources.</li> </ul> <p><b>Key recommendations for support for individuals, families, whānau and caregivers</b></p> <ul style="list-style-type: none"> <li>▪ The values, knowledge, preferences and cultural perspectives of the whānau and family should be integrated, respected and evident in services and resources. (Grade B: Fair evidence)</li> <li>▪ Individuals, whānau and family members need to know how to find and access information and support. Health providers, support groups, whānau and iwi work together to develop appropriate support services for individuals, whānau and families to ensure sources of support and information are available. (Grade B: Fair evidence)</li> <li>▪ A key service to support whānau and families is the provision of information about long COVID. Information needs to be accessible to all people, including translated material, easy-to-read versions and developmentally appropriate information. Support groups and government should work in close association to ensure all information is kept up to date. (Grade B: Fair evidence)</li> <li>▪ Individualised support should be available to people with long COVID, their whānau and family who require assistance to manage their physical and mental wellbeing and healthcare needs. (Grade B: Fair evidence)</li> <li>▪ Medical and healthcare practitioners should take into account the symptomatology of their long COVID clients/patients and adapt their practices and procedures accordingly. (Grade B: Fair evidence)</li> <li>▪ Vaccination discussions with whānau with respect to starting or continuing childhood immunisation programmes 3 months following COVID-19. (Grade A: Good evidence)</li> <li>▪ Methodologically rigorous research is needed to examine the effectiveness of current evaluation methods and treatments used to address long COVID. (Grade B: Fair evidence)</li> <li>▪ A coordinated approach to planning and implementing services should be developed to meet the identified needs of an individual/whānau with long COVID, including linkage or integration and coordination of multiple services. (Grade C: Expert opinion)</li> <li>▪ The use of specific outcomes measures should align with the recommendations from post-COVID core outcome set. Consider paediatric specific core outcome if available set. (Grade C: Expert opinion)</li> </ul> <p><b>Key recommendations for service provision to Māori Whānau</b></p> <ul style="list-style-type: none"> <li>▪ Support and funding for the community development of information packages in Te Reo Māori about long COVID using a range of media. (Grade B: Fair evidence)</li> </ul> |
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|  | <ul style="list-style-type: none"> <li>▪ Establishing a kaimanaaki who could work as a resource across sectors, to support individuals and whānau experiencing long COVID. A national network for the professional support for the kaimanaaki may be useful to encourage. (Grade B: Fair evidence)</li> <li>▪ Support for Māori led research and long COVID is put in place and institutionally developed. (Grade B: Fair evidence)</li> <li>▪ Support a development strategy to facilitate increasing the capacity and capability of the Māori health workforce and disability workforce where there is ongoing collaboration and access to specialist training. (Grade B: Fair evidence)</li> <li>▪ Support for Rongoa and traditional Māori healthcare. (Grade C: Expert opinion)</li> </ul> <p><b>Key recommendations for Pacific Peoples and fanau</b></p> <ul style="list-style-type: none"> <li>▪ Long COVID information packages in the widely spoken Pacific languages (Tongan, Samoan, Cook Island Māori, Niuean, Fijian, Tokelauan, Kiribati) using a range of media should be developed. This information could be distributed through Pacific people, mainstream and community providers of health, employment, education and disability services. (Grade C: Expert opinion)</li> <li>▪ Systems responsibility to support fanau-based models of care with Pacific Peoples providers and community organisations eg. Churches with expertise, resources and training. (Grade B: Fair evidence)</li> <li>▪ A programme of research that would provide baseline information regarding long COVID and Pacific people should be developed. (Grade C: Expert opinion)</li> <li>▪ A targeted recruitment and development strategy to support increasing the capacity and capability of the Pacific people health workforce and disability workforce should be developed. (Grade C: Expert opinion)</li> <li>▪ A whole of system response should be developed aimed at improving the cultural safety of the mainstream workforce to acquire knowledge and understanding of Pacific cultural values and world views and appropriately apply this to their work. (Grade B: Fair evidence)</li> </ul> <p><b>Key recommendations for disabled people and their family/whanau</b></p> <ul style="list-style-type: none"> <li>▪ Reduce barriers for disabled people to access community mobility and healthcare services. (Grade C: Expert opinion)</li> <li>▪ Apply an Enabling Good Lives approach; family support, living environment and context of their life to be taken into account. (Grade C: Expert opinion)</li> <li>▪ Assess impacts to caregivers as well as the disabled person. Parents and Caregivers operate in environments that create additional risks. (Grade C: Expert opinion)</li> <li>▪ Existing peer support groups can be accessed for all individuals requiring informal supports. (Grade C: Expert opinion)</li> </ul> <p>Good practice point for disabled people and their family/whanau</p> <ul style="list-style-type: none"> <li>▪ Individualised supports offered to each person need to be customised/tailored for disabled people, e.g., experts in disabled rehabilitation are involved and accessible for long COVID management. (Grade C: Expert opinion)</li> </ul> |
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|  | <ul style="list-style-type: none"> <li>▪ Disabled people are prioritised for assessment and treatment. (Grade C: Expert opinion)</li> <li>▪ Accessible communication, information and treatment options are planned for and available e.g., digital modifications, ramps, transport, Speech Language therapy interpreters, Braille, easy read etc. (Grade C: Expert opinion)</li> </ul> <p><b>Key recommendations for rural communities</b></p> <ul style="list-style-type: none"> <li>▪ Reduce access barriers for rural communities by providing services through the services that are established in those communities. (Grade C: Expert opinion)</li> <li>▪ Utilise mobile, telehealth and “pop up” services in rural communities where people face significant problems with transportation. (Grade C: Expert opinion)</li> <li>▪ Provide supported transport, and where appropriate accommodation services for people who must access urban services. (Grade C: Expert opinion)</li> <li>▪ Measure the impact of rural dwelling on access to services and where access is identified as significant use rural communities and providers to find “rural proof” solutions. (Grade C: Expert opinion)</li> </ul> <p>Good practice point for rural communities</p> <ul style="list-style-type: none"> <li>▪ Mobile clinics make services more accessible. . (Grade C: Expert opinion)</li> <li>▪ Telehealth programmes make services more accessible. (Grade C: Expert opinion)</li> <li>▪ Use of Marae and non-health community services as a resource. (Grade C: Expert opinion)</li> </ul> <p><b>Recommendations for older people and aged residential care perspectives</b></p> <p>Good practice point for older people and aged residential care perspectives</p> <ul style="list-style-type: none"> <li>▪ Older adults presenting with mobility issues and long COVID symptoms are to be referred for a mobility assessment. (Grade C: Expert opinion)</li> <li>▪ Older adults presenting with communication issues and long COVID symptoms are to be referred for a speech-language therapy assessment. (Grade C: Expert opinion)</li> <li>▪ Older adults presenting with nutritional and swallowing issues and long COVID symptoms are to be referred for a speech-language therapy and/or dietitian assessment. (Grade C: Expert opinion)</li> <li>▪ Older adults with a higher BMI presenting with symptoms of long COVID are to be assessed and referred for support with breathlessness, fatigue, mobility assessment and in performing daily activities. (Grade C: Expert opinion)</li> <li>▪ Older adults with presentations of multiple symptoms will benefit from multidisciplinary help including additional medical and psychological support. (Grade C: Expert opinion)</li> </ul> |
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**Key:** BMI - body mass index; CFS - chronic fatigue syndrome; FND- functional neurological disorder; ME - myalgic encephalomyelitis; MIS-C - multi system inflammatory syndrome in children; PEM - post exercise malaise; PESE – post exertional symptom exacerbation; PIMS-Ts - paediatric inflammatory multisystem syndrome temporally associated with SARS-Cov2; PoTS - postural orthostatic tachycardia syndrome; PTSD - post traumatic stress disorder.

## Appendix 4 Data extraction tables for clinical guidelines and or models of care relating to specific long COVID sequelae

### Appendix 4.1 Data extraction table for Long COVID-19: A Primer for Cardiovascular Health Professionals, on Behalf of the Canadian Cardiovascular Society Rapid Response Team

| Clinical guideline and or model of care characteristics  |  |
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| <b>Endorsing Organisation</b>  | The Canadian Cardiovascular Society (CCS) Rapid Response Team  |
| <b>Title</b>   | Long COVID-19: A Primer for Cardiovascular Health Professionals, on Behalf of the CCS Rapid Response Team  |
| <b>Country</b>   | Canada   |
| <b>Date Published</b>  | 12 March 2021  |
| <b>URL</b>   | <a href="https://doi.org/10.1016/j.cjca.2021.05.011">https://doi.org/10.1016/j.cjca.2021.05.011</a>  |
| <b>National or regional</b>  | National   |
| <b>Adapted from previous guidelines and or model of care?<br/>If so which guidelines and or model of care was it adapted from?</b> | N/A  |
| <b>Update(s) planned (including dates)</b>   | N/R  |
| Definition and diagnosis   |  |
| <b>Specific long COVID sequelae referred to</b>  | Cardiac-related complications  |
| <b>Definition of long COVID used in the guideline and or model of care</b>   | <p><b>Long COVID-19</b></p> <ul style="list-style-type: none"> <li>Is commonly used to define any patient with persistent symptoms after acute COVID-19 (ie, after 4 weeks).<br/>(Refers to the NICE definition of long COVID in the supplemental material)</li> </ul>   |
| <b>Recommendations for diagnosis of long COVID</b>   | <p><b>Symptoms of cardiac-related complications</b></p> <ul style="list-style-type: none"> <li>Persistent or new unexplained chest pain</li> <li>Shortness of breath</li> <li>Frequent palpitations</li> <li>Postural light headedness</li> </ul> <p><b>Cardiac-related complications assessment recommendations</b></p> |

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|   | <ul style="list-style-type: none"> <li>▪ The Canadian Cardiovascular Society Rapid Response Team has placed an emphasis on physical examination and noninvasive assessment using local expertise and periodic surveillance, especially among those with preexisting cardiac conditions or multisystem disease.</li> <li>▪ Chest pain – potential aetiologies:             <ul style="list-style-type: none"> <li>○ Myopericarditis. Suggested investigations include: ECG, cardiac troponin, echocardiography, cardiac magnetic resonance imaging</li> <li>○ Ischemic heart disease. Suggested investigations include: ECG, functional test for ischemia</li> </ul> </li> <li>▪ Shortness of breath – potential aetiologies:             <ul style="list-style-type: none"> <li>○ Congestive heart failure. Suggested investigations include: ECG, BNP/NT-proBNP, echocardiography</li> <li>○ Deconditioning. Suggested investigations include: Pedometer, cardiopulmonary exercise test</li> <li>○ Pulmonary scarring, thromboembolic disease, pulmonary hypertension. Suggested investigations include: Chest radiograph, pulmonary function testing, computed tomography imaging</li> </ul> </li> <li>▪ Palpitations – potential aetiologies:             <ul style="list-style-type: none"> <li>○ Arrhythmia. Suggested investigations include: ECG, Holter monitoring</li> <li>○ Inappropriate sinus tachycardia, cardiac dysautonomia. Suggested investigations include: ECG, active standing test</li> </ul> </li> <li>▪ Orthostatic light headedness – potential aetiologies:             <ul style="list-style-type: none"> <li>○ Cardiac dysautonomia. Suggested investigations include: Postural vital signs, active standing test</li> </ul> </li> </ul> |
| <b>Management and treatment</b>   |  |
| <p><b>Recommendations for treatment and or management of long COVID</b></p> | <p><b>Cardiac-related complications treatment recommendations</b></p> <ul style="list-style-type: none"> <li>▪ Patients with new cardiac findings or symptoms should be managed using contemporary treatments, similar to patients without a history of COVID-19 infection.</li> <li>▪ Suggested treatments:             <ul style="list-style-type: none"> <li>○ Established cardiovascular disease: Continue with guideline-based goal-directed therapy</li> <li>○ Myopericarditis: Nonsteroidal anti-inflammatory drug, colchicine</li> <li>○ Cardiac dysautonomia (orthostatic hypotension, persistent sinus tachycardia, Postural Orthostatic Tachycardia Syndrome-like syndrome): Hydration, salt supplementation, compression garments; Selective use of pharmacotherapies including midodrine, beta blockers, ivabradine</li> <li>○ Post exertional malaise: Pacing - finding the individual’s envelope, paying attention to the level of triggers, which might be physical, emotional, or cognitive; the individual adapting to their envelope; learning to control triggers; and expanding their envelope with gradual progression and adaptation</li> </ul> </li> <li>▪ Additional considerations should include baseline health, premorbid function, biomechanical assessments, exercise prescription, and a holistic patient review; much of which could be delivered via telemedicine.</li> </ul>  |
| <b>Service planning</b>   |  |



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| <b>Recommendations for service planning for long COVID</b> | A multidisciplinary team rehabilitation service is required that consists of nurses, physiotherapists, physiatrists, exercise specialists, neurologists, psychiatrists, respirologists, rehabilitation experts, and cardiologists to coordinate an individualized plan including in-person and electronic supports. |
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**Key:** BNP-brain natriuretic peptide; ECG- electrocardiogram; NT-proBNP - N-terminal pro b-type natriuretic peptide; N/A- not applicable; N/R- not reported.

## Appendix 4.2 Data extraction table for Swiss Recommendations for the Follow-Up and Treatment of Pulmonary Long COVID

| Clinical guideline and or model of care characteristics  |  |
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| <b>Endorsing Organisation</b>  | Swiss COVID Lung Study Group & the Swiss Society of Pulmonology  |
| <b>Title</b>   | Swiss Recommendations for the Follow-Up and Treatment of Pulmonary Long COVID  |
| <b>Country</b>   | Switzerland  |
| <b>Date Published</b>  | 4 June 2021  |
| <b>URL</b>   | <a href="https://doi.org/10.1159/000517255">https://doi.org/10.1159/000517255</a>  |
| <b>National or regional</b>  | National   |
| <b>Adapted from previous guidelines and or model of care?<br/>If so which guidelines and or model of care was it adapted from?</b> | N/A  |
| <b>Update(s) planned (including dates)</b>   | N/R  |
| Definition and diagnosis   |  |
| <b>Specific long COVID sequelae referred to</b>  | Pulmonary  |
| <b>Definition of long COVID used in the guideline and or model of care</b>   | <p><b>Acute COVID-19</b></p> <ul style="list-style-type: none"> <li>Signs and symptoms of COVID-19 for up to 4 weeks.</li> </ul> <p><b>Ongoing symptomatic COVID-19</b></p> <ul style="list-style-type: none"> <li>Signs and symptoms of COVID-19 from 4 weeks up to 12 weeks.</li> </ul> <p><b>Post-COVID-19 syndrome</b></p> <ul style="list-style-type: none"> <li>Signs and symptoms that develop during or after an infection consistent with COVID-19, continue for more than 12 weeks and are not explained by an alternative diagnosis.</li> </ul> <p><b>Long COVID</b></p> <ul style="list-style-type: none"> <li>Long COVID describes signs and symptoms that continue or develop after acute COVID-19; it includes both ongoing symptomatic COVID-19 (from 4 to 12 weeks) and post-COVID-19 syndrome (12 weeks or more).</li> </ul> |
| <b>Recommendations for diagnosis of long COVID</b>   | <p><b>Recommendations for diagnosis</b></p> <ul style="list-style-type: none"> <li>Patients hospitalised for COVID-19 should have a pulmonary assessment including pulmonary function tests. (Strong consensus recommendation) The suggested time frame is within 3 months after infection. (Not consensus based).</li> </ul>  |

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|  | <ul style="list-style-type: none"> <li>▪ Symptomatic subjects affected by COVID-19, including those with mild disease, should benefit from a pulmonary follow-up (Strong consensus recommendation). The suggested time frame is within 3 months after infection (Not consensus based).</li> <li>▪ Persistent respiratory symptoms after COVID-19 should be investigated by a pulmonary follow-up including plethysmography, diffusion capacity measurement, and blood gases analysis (Strong consensus recommendation).</li> <li>▪ Exercise testing (e.g., 6 minute walking test or equivalent) is recommended after COVID-19. (Weak consensus recommendation). 6 minute walking test has been employed to evaluate individuals after COVID-19 to diagnose exercise-related hypoxia and evaluate decreased exercise capacity.</li> <li>▪ Chest CT scan is recommended to be routinely performed in patients with persisting respiratory symptoms after COVID-19. (moderate consensus recommendation)</li> <li>▪ Cardio-pulmonary exercise test is recommended to be routinely performed after COVID-19 with persistent symptoms (moderate consensus recommendation).</li> <li>▪ A post-COVID-19 pulmonary follow-up includes, but is not limited to, specific assessment of respiratory complaints and history of COVID-19, physical examination and appropriate lung function exploration. The pulmonary follow-up can be backed by specific and generic quality of life questionnaires, specific laboratory investigations (e.g., SARS-CoV2 antibody confirmation), and imaging studies.</li> </ul> |
| <b>Management and treatment</b>                                      |   |
| <b>Recommendations for treatment and or management of long COVID</b> | <b>Recommendations for management</b> <ul style="list-style-type: none"> <li>▪ Patients with persistent symptoms after COVID-19 are recommended to have access to specialized multidisciplinary Post-COVID-19 clinics or networks (moderate consensus recommendation).</li> <li>▪ Patients after COVID-19 who present with new obstructive lung disease are recommended to be offered empiric topic inhaled or systemic steroid treatment (moderate consensus recommendation).</li> <li>▪ Patients after COVID-19 who present with new obstructive lung disease are recommended to have empiric topic inhaled or systemic steroid treatment (moderate consensus recommendation).</li> <li>▪ Patients after COVID-19 who present with persistent cough are recommended to have empiric inhaled topic steroids (moderate consensus recommendation).</li> <li>▪ Patients after COVID-19 who present with interstitial abnormalities after exclusion of an active infection are recommended to be evaluated to receive an empiric systemic steroid trial (moderate consensus recommendation).</li> <li>▪ Patients after COVID-19 who present with persistent respiratory symptoms are recommended to undergo a rehabilitation program (moderate consensus recommendation).</li> </ul>   |
| <b>Service planning</b>  |   |
| <b>Recommendations for service planning for long COVID</b>           | N/R   |

**Key:** CT - computed tomography; N/A - not applicable; N/R - not reported.

### Appendix 4.3 Data extraction table for multi-disciplinary collaborative consensus guidance statement on the assessment and treatment of fatigue in patients with post-acute sequelae of SARS-CoV-2 infection

| Clinical guideline and or model of care characteristics  |  |
|--|--|
| <b>Endorsing Organisation</b>  | The American Academy of Physical Medicine and Rehabilitation (AAPM&R) Multi-Disciplinary Post-acute Sequelae of SARS-CoV-2 (PASC) Collaborative  |
| <b>Title</b>   | Multidisciplinary collaborative consensus guidance statement on the assessment and treatment of fatigue in Patients with PASC  |
| <b>Country</b>   | US   |
| <b>Date Published</b>  | 4 August 2021  |
| <b>URL</b>   | <a href="https://doi.org/10.1002/pmrj.12684">https://doi.org/10.1002/pmrj.12684</a>  |
| <b>National or regional</b>  | National   |
| <b>Adapted from previous guidelines and or model of care?<br/>If so which guidelines and or model of care was it adapted from?</b> | The Centers for Disease Control and Prevention has developed treatment recommendations for ME/CFS that have been used to help develop the current treatment recommendations for PASC-related fatigue.  |
| <b>Update(s) planned (including dates)</b>   | The PASC Collaborative will be polled every 3 months following the release of each guidance statement to determine if revisions are needed to align with current practice.   |
| Definition and diagnosis   |  |
| <b>Specific long COVID sequelae referred to</b>  | Fatigue  |
| <b>Definition of long COVID used in the guideline and or model of care</b>   | <p><b>PASC</b></p> <ul style="list-style-type: none"> <li>▪ PASC can be defined as continuation of symptoms beyond 3 or 4 weeks from the onset of acute infection.</li> <li>▪ Other definitions of PASC include symptoms lasting longer than 3 months.</li> </ul>  |
| <b>Recommendations for diagnosis of long COVID</b>   | <p><b>Assessment</b></p> <ul style="list-style-type: none"> <li>▪ Patients should be assessed for fatigue patterns throughout their normal day to activity</li> <li>▪ Patients should be assessed for their responses to initiating and escalating activity on their fatigue.</li> <li>▪ Patients should be evaluated for changes in daily functioning and activity levels.</li> <li>▪ Patients' physical functioning and endurance should be assessed to inform activity and therapy recommendations. (Examples of tests that can be chosen based on an individual's activity tolerance: 30 s sit to stand; 2-min step (seated or standing); 6 min walk test; 10 m walk test).</li> <li>▪ Clinicians should assess for changes in activities of daily living, independent activities of daily living, school, work, and avocational (i.e. hobbies).</li> <li>▪ A full patient history with review of preexisting conditions should be conducted.</li> </ul> |

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|   | <ul style="list-style-type: none"> <li>▪ Patients should be evaluated for conditions that may exacerbate fatigue symptoms and warrant further testing and potential subspecialty referral. Particular areas include:             <ul style="list-style-type: none"> <li>○ Sleep</li> <li>○ Mood, including anxiety, depression and PTSD. Note: Patients often report dissatisfaction with their care because of their persistent symptoms being attributed to psychological factors. It is important to note that mood disorders may be secondary to persistent medical issues or one of many factors leading to fatigue.</li> <li>○ Cardiopulmonary</li> <li>○ Autoimmune</li> <li>○ Endocrine</li> </ul> </li> <li>▪ A medication review should be conducted to investigate medications that may be contributing to fatigue. Of note, antihistamine, anticholinergic, and antidepressant/anxiolytic medications can contribute to fatigue in patients with PASC.</li> <li>▪ The following basic lab workup should be considered in new patients or those without lab workup in the 3 months before visit including complete blood count with differential, chemistries including renal and hepatic function tests, thyroid stimulating hormone, c-reactive protein or erythrocyte sedimentation rate, and creatinine kinase.             <ul style="list-style-type: none"> <li>○ Other laboratory tests may be considered based on the results of these tests or if there is specific concern for comorbid conditions.</li> </ul> </li> </ul> |
| <b>Management and treatment</b>   |  |
| <p><b>Recommendations for treatment and or management of long COVID</b></p> | <p><b>PASC fatigue treatment recommendations:</b></p> <ul style="list-style-type: none"> <li>▪ Begin an individualized and structured, titrated return to activity program.</li> <li>▪ Discuss energy conservation strategies.</li> <li>▪ Encourage a healthy dietary pattern and hydration.</li> <li>▪ Treat, in collaboration with appropriate specialists, underlying medical conditions, such as pain, insomnia/sleep disorders (including poor sleep hygiene), and mood issues that may be contributing to fatigue.</li> </ul>  |
| <b>Service planning</b>   |  |
| <p><b>Recommendations for service planning for long COVID</b></p>           | <p>N/R</p>   |

**Key:** CFS - chronic fatigue syndrome; ME - myalgic encephalomyelitis; N/R – not reported; PASC – post acute sequelae of SARS-CoV-2 infection; PTSD – post traumatic stress disorder.

## Appendix 4.4 Data extraction table for Neurological manifestations of post-COVID-19 syndrome S1-guideline of the German society of neurology

| Clinical guideline and or model of care characteristics  |   |
|--|---|
| <b>Endorsing Organisation</b>  | German Neurological Society   |
| <b>Title</b>   | Neurological manifestations of post-COVID-19 syndrome S1-guideline of the German society of neurology   |
| <b>Country</b>   | Germany   |
| <b>Date Published</b>  | December 2021   |
| <b>URL</b>   | <a href="https://doi.org/10.1186/s42466-022-00191-y">https://doi.org/10.1186/s42466-022-00191-y</a>   |
| <b>National or regional</b>  | National  |
| <b>Adapted from previous guidelines and or model of care?<br/>If so which guidelines and or model of care was it adapted from?</b> | N/A   |
| <b>Update(s) planned (including dates)</b>   | It is currently under revision (17 August 2022). Stated to be valid until 31 August 2023.   |
| Definition and diagnosis   |   |
| <b>Specific long COVID sequelae referred to</b>  | Neurological manifestations   |
| <b>Definition of long COVID used in the guideline and or model of care</b>   | <p><b>Long COVID</b></p> <ul style="list-style-type: none"> <li>▪ Clinical symptoms more than 4 weeks after COVID-19.</li> </ul> <p><b>Post-COVID-19 Syndrome</b></p> <ul style="list-style-type: none"> <li>▪ Clinical symptoms that occur during or after an illness compatible with COVID-19, persisting for at least 2 months, fluctuating in occurrence and cannot be explained by any other diagnosis. The acute infection dates back at least 12 weeks.</li> </ul> |
| <b>Recommendations for diagnosis of long COVID</b>   | <p><b>Symptoms</b></p> <ul style="list-style-type: none"> <li>▪ The most common neurological complaints are: <ul style="list-style-type: none"> <li>○ fatigue</li> <li>○ concentration and memory disorders</li> <li>○ headache</li> <li>○ vertigo</li> <li>○ myalgia and neuropathy</li> <li>○ smell and taste disturbances.</li> </ul> </li> <li>▪ Neurological diseases have been reported such as:</li> </ul>   |

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|  | <ul style="list-style-type: none"> <li>○ cerebrovascular disease (including stroke and transient ischemia)</li> <li>○ epileptic seizures</li> <li>○ myelitis</li> <li>▪ Peripheral neurological diseases such as: <ul style="list-style-type: none"> <li>○ Guillain-Barré syndrome</li> <li>○ cranial nerve deficits</li> <li>○ myositis</li> <li>○ plexopathies</li> </ul> </li> <li>▪ Rare cases of autoimmune encephalomyelitis were reported 3 months after COVID-19.</li> </ul> <p><b>Post-COVID-19 associated symptoms and diagnostics</b></p> <ul style="list-style-type: none"> <li>▪ A comprehensive—ideally interdisciplinary—diagnostic assessment should be initiated in patients who complain about residual or new symptoms more than 3 months after the acute infection.</li> <li>▪ If immune involvement is detected, immunomodulatory therapy may be considered as an individual treatment attempt.</li> </ul> <p><b>Cognitive disorders and fatigue</b></p> <ul style="list-style-type: none"> <li>▪ Cognitive deficits found both in the subacute stage and in the further course after COVID-19 comprise executive functioning, processing speed, category fluency, memory encoding and recall.</li> <li>▪ If self-reported cognitive deficits occur, a cognitive screening assessment e.g. the Montreal Cognitive Assessment should be performed. If pathological results are detected and the symptoms are persistent for several months with restrictions regarding the activities of daily life, further examination is indicated.</li> <li>▪ Diagnostics include the examination of serum and cerebrospinal fluid including CNS autoantibodies against intracellular and surface antigens and neurodegenerative markers, cerebral imaging, and detailed neuropsychological assessment.</li> <li>▪ Self-report questionnaires such as the Fatigue Scale, the Fatigue Severity Scale or the Fatigue Assessment Scale should be used to assess the symptoms and severity of fatigue.</li> </ul> <p><b>Headache</b></p> <ul style="list-style-type: none"> <li>▪ Self-report instruments (e.g. Brief Pain Inventory) should be used to assess symptoms including the severity of chronic pain. Depending on the clinical presentation and examination, an extended laboratory examination can be carried out to rule out other (e.g. rheumatological) causes. MRI should be performed in individual cases to exclude structural causes.</li> </ul> <p><b>Hyposmia/anosmia and hypogeusia/ageusia</b></p> <ul style="list-style-type: none"> <li>▪ Hyposmia/hypogeusia or anosmia/ageusia should be objectified e.g. using the SS-16 item sniffin sticks test and taste test. Neurological and/or ear, nose and throat presentation should include a thorough case history excluding competing or alternative causes. Further laboratory diagnostic and endoscopy may be considered.</li> </ul> <p><b>Myalgia, muscle weakness and neuropathy</b> (<i>Adapted from existing guidelines</i>)</p> |
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|  | <ul style="list-style-type: none"> <li>▪ Subsequent to case history and neurological examination, a laboratory investigation of blood including sedimentation rate, myoglobin, creatine kinase and myositis antibodies if clinically suspected, as well as examination of cerebrospinal fluid are recommended.</li> <li>▪ An electrophysiological examination is indicated. These recommendations are in line with existing guidelines German regarding muscular and neuro muscular disorder.</li> </ul>  |
| <b>Management and treatment</b>                                      |   |
| <b>Recommendations for treatment and or management of long COVID</b> | <p><b>Post-COVID-19 associated symptoms and therapy</b></p> <p><b>Cognitive disorders and fatigue</b></p> <ul style="list-style-type: none"> <li>▪ To date there are no established and effective medical treatment options for post-viral fatigue and cognitive impairment, as well as related conditions such as Myalgic Encephalomyelitis/Chronic Fatigue Syndrome.</li> <li>▪ If there are indications of autoimmunity, therapeutic approaches including corticosteroids, intravenous immunoglobulins or therapeutic apheresis can be administered depending on risk and expected benefit.</li> <li>▪ A causal therapy for fatigue is unknown. Non-drug therapeutic approaches such as relaxation techniques, moderate physical activity, and acquisition of adequate coping behavior strategies in addition to psychotherapeutic or psychopharmacological treatment are recommended.</li> </ul> <p><b>Headache</b></p> <ul style="list-style-type: none"> <li>▪ To date headache related to COVID-19 is treated in analogy to chronic tension headache. Prophylactic treatment options including amitriptyline are recommended.</li> <li>▪ Therapeutic approaches follow the existing guidelines of the German Society of Neurology.</li> </ul> <p><b>Hyposmia/anosmia and hypogeusia/ageusia</b></p> <ul style="list-style-type: none"> <li>▪ Constant and structured olfactory training is recommended.</li> </ul> <p><b>Myalgia, muscle weakness and neuropathy</b></p> <ul style="list-style-type: none"> <li>▪ Therapeutic procedures depend on diagnostic findings and are applied according to existing guidelines.</li> <li>▪ If laboratory results obtain unremarkable, symptomatic treatment can be tried, e.g. administering gabapentine or pregabalin. Physiotherapy and moderate exercise should be implemented.</li> </ul> |
| <b>Service planning</b>  |   |
| <b>Recommendations for service planning for long COVID</b>           | An interdisciplinary treatment including internal, psychosomatic, and psychiatric expertise is crucial in diagnostic and treatment of post-COVID-19 syndrome patients.  |

**Key:** CNS - central nervous system, MRI - magnetic resonance imaging; N/A - not applicable.



### Appendix 4.5 Data extraction table for Multi-disciplinary collaborative consensus guidance statement on the assessment and treatment of breathing discomfort and respiratory sequelae in patients with post-acute sequelae of SARS-CoV-2 infection

| Clinical guideline and or model of care characteristics  |   |
|--|---|
| <b>Endorsing Organisation</b>  | American Academy of Physical Medicine and Rehabilitation Multi-Disciplinary Post-acute Sequelae of SARS-CoV-2 (PASC) Collaborative  |
| <b>Title</b>   | Multi-disciplinary collaborative consensus guidance statement on the assessment and treatment of breathing discomfort and respiratory sequelae in patients with PASC  |
| <b>Country</b>   | US  |
| <b>Date Published</b>  | 13 December 2021  |
| <b>URL</b>   | <a href="https://doi.org/10.1002/pmjr.12744">https://doi.org/10.1002/pmjr.12744</a>   |
| <b>National or regional</b>  | National  |
| <b>Adapted from previous guidelines and or model of care?<br/>If so which guidelines and or model of care was it adapted from?</b> | N/A   |
| <b>Update(s) planned (including dates)</b>   | The PASC Collaborative will be polled every 3 months following the release of each guidance statement to determine if revisions are needed to align with current practice.  |
| Definition and diagnosis   |   |
| <b>Specific long COVID sequelae referred to</b>  | Breathing discomfort and respiratory sequelae   |
| <b>Definition of long COVID used in the guideline and or model of care</b>   | <p><b>PASC</b></p> <ul style="list-style-type: none"> <li>▪ Symptoms that do not improve 1 month after acute COVID-19 symptom onset.</li> </ul>   |
| <b>Recommendations for diagnosis of long COVID</b>   | <p><b>Symptoms of breathing discomfort and respiratory sequelae</b></p> <ul style="list-style-type: none"> <li>▪ Common symptoms include shortness of breath at rest;             <ul style="list-style-type: none"> <li>○ Disproportionate shortness of breath with activity</li> <li>○ Chest discomfort that may manifest as pain tightness constriction, and/or pressure</li> <li>○ Inability to take a full deep breath</li> <li>○ New or progressive cough</li> <li>○ Chest congestion</li> </ul> </li> <li>▪ These symptoms frequently result in limited activity tolerance.</li> </ul> <p><b>Example measures of symptoms and activity related to breathing discomfort</b></p> |

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|  | <ul style="list-style-type: none"> <li>▪ Multidimensional dyspnea profile assesses sensation and severity of dyspnea sensation.</li> <li>▪ Modified Borg Dyspnea Scale is a means of quantifying the severity of the dyspnea sensation.</li> <li>▪ Modified Medical Research Council dyspnea scale assesses impact of dyspnea on physical activity.</li> <li>▪ Duke Activity Status Index assesses limitations in physical activity.</li> </ul> <p><b>PASC breathing discomfort assessment recommendations</b></p> <ul style="list-style-type: none"> <li>▪ Clinicians should conduct a full patient history including review of predisposing comorbidities, characterising course of acute COVID-19 (e.g., medications received, oxygen saturation during acute illness, need for intensive care unit admission and mechanical ventilation), use of supplemental oxygen during or after acute illness, activity level since COVID-19, medications, and any new diagnoses or complications acquired following the index illness.</li> <li>▪ Clinicians should systematically characterize breathing discomfort, including use of standard measures to describe and quantify the discomfort, and understand activity level that patients can achieve. The contribution of other factors that limit activity, including fatigue with post-exertional malaise and impaired hemodynamic response to activity (eg, inappropriate sinus tachycardia), must be considered in this activity assessment.</li> <li>▪ Clinicians should assess the trajectory of breathing discomfort over time (i.e., improving, worsening, or unchanged) to triage need for further workup.</li> <li>▪ Obtain pre-COVID-19 history including baseline respiratory symptoms and exercise capacity; obtain and review prior and recent pulmonary testing, including pulmonary function tests, chest radiograph, and chest computed tomography scan, when available.</li> <li>▪ In addition to full vital signs and physical exam, assess pulse oximetry while walking in a clinic office, breathing ambient air, to assess for desaturation. The pace and/or duration of exertion during this test can be increased, as tolerated and feasible.</li> <li>▪ Consider performing PFTs in patients with persistent breathing discomfort that is not improving at least 8 weeks after acute COVID-19, or in patients who develop new onset or worsening breathing discomfort later in the post-COVID course. Consider consultation with a pulmonologist for new or progressive abnormalities.</li> <li>▪ Chest imaging should be considered in evaluating breathing discomfort in the setting of ambulatory desaturation, abnormal pulmonary exam, impairments on pulmonary function testing, or on an individual basis for other clinical concerns. Chest radiographs are an appropriate initial study for most patients. Consider consultation with a pulmonologist or PASC clinic to guide imaging.</li> <li>▪ Transthoracic echocardiography, cardiac stress testing, and cardiopulmonary exercise testing are not routinely recommended to evaluate breathing discomfort alone after COVID-19. However, these tests may be valuable to consider in the context of a patient's associated symptoms (e.g. chest pain) and treatment plan (e.g. rehabilitation therapy) on an individual basis in consultation with a PASC clinic, cardiologist, pulmonologist, or pulmonary rehabilitation physiatrist.</li> </ul> |
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|   | <ul style="list-style-type: none"> <li>▪ Consider evaluation by an otolaryngologist for abnormal upper airway breath sounds or voice changes, including stridor, hoarseness, or unexplained episodic breathing discomfort, especially in patients with a history of endotracheal intubation and/or tracheostomy following critical illness related to COVID-19.</li> <li>▪ For patients undergoing rehabilitation therapy, obtain standardised measures of activity performance. For patients physically limited by fatigue with post-exertional malaise, neurological impairment, or other impairments, perform alternative measures of activity performance.</li> </ul>  |
| <b>Management and treatment</b>   |  |
| <p><b>Recommendations for treatment and or management of long COVID</b></p> | <p><b>PASC breathing discomfort treatment recommendations</b></p> <ul style="list-style-type: none"> <li>▪ Consider evaluation by a pulmonologist for any of the following, based on assessment recommendations: <ul style="list-style-type: none"> <li>○ Abnormal PFTs and/or chest imaging</li> <li>○ Abnormal pulmonary exam, which is persistent, unexplained, and/or unresolved after management in primary care setting</li> <li>○ Persistent productive cough and/or difficulty clearing airway secretions</li> <li>○ Oxygen desaturation with activity</li> </ul> </li> <li>▪ Referral to a pulmonologist for breathing discomfort in the absence of these abnormalities can be considered on an individual basis when persistent or unexplained.</li> <li>▪ Patients requiring home oxygen should be provided a portable oxygen device whenever possible to maximize mobility, ability to participate in rehabilitation, and quality of life. Oxygen should be appropriately titrated to an ambulatory saturation range based on established standards, to facilitate progress with rehabilitation and activity. Oxygen therapy should be provided for the following patient groups: <ul style="list-style-type: none"> <li>○ Group I—patients with significant hypoxemia evidenced by any of the following: <ul style="list-style-type: none"> <li>▪ An arterial PO<sub>2</sub> at or below 55 mm Hg, or an arterial oxygen saturation at or below 88%, taken at rest, breathing ambient air.</li> <li>▪ An arterial PO<sub>2</sub> at or below 55 mm Hg, or an arterial oxygen saturation at or below 88%, taken during sleep for a patient who demonstrates an arterial PO<sub>2</sub> at or above 56 mm Hg, or an arterial oxygen saturation at or above 89%, while awake, or a greater than normal fall in oxygen level during sleep (a decrease in arterial PO<sub>2</sub> more than 10 mm Hg, or decrease in arterial oxygen saturation more than 5%) associated with symptoms or signs reasonably attributable to hypoxemia (e.g., impairment of cognitive processes and nocturnal restlessness or insomnia).</li> <li>▪ An arterial PO<sub>2</sub> at or below 55 mm Hg or an arterial oxygen saturation at or below 88%, taken during exercise for a patient who demonstrates an arterial PO<sub>2</sub> at or above 56 mm Hg, or an arterial oxygen saturation at or above 89%, during the day while at rest.</li> </ul> </li> <li>○ Group II—patients whose arterial PO<sub>2</sub> is 56 to 59 mm Hg or whose arterial blood oxygen saturation is 89% or higher, if there is evidence of:</li> </ul> </li> </ul> |

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|  | <ul style="list-style-type: none"> <li>▪ Dependent edema suggesting congestive heart failure, or</li> <li>▪ Pulmonary hypertension or cor pulmonale, determined by measurement of pulmonary artery pressure, gated blood pool scan, echocardiogram, or “P” pulmonale on electrocardiography (P wave greater than 3 mm in standard leads II, III, or AVFL), or</li> <li>▪ Erythrocythemia with a hematocrit greater than 56%.</li> </ul> <ul style="list-style-type: none"> <li>▪ Refer patients with persistent breathing discomfort resulting in activity limitation for individualized rehabilitation therapy:             <ul style="list-style-type: none"> <li>○ If patients have accompanying fatigue with post-exertional malaise and/or dysautonomia, the most physically limiting factor should dictate the pace of activity as these can be worsened by over-activity.</li> <li>○ If patients are awaiting PFTs, they can undergo general rehabilitation therapy while waiting if they are not thought to require further cardiac clearance prior to exercise.</li> <li>○ Consider physiological and subjective response to activity to determine the appropriate paced approach, similar to other aspects of PASC including fatigue and dysautonomia.</li> <li>○ Patients with PFT abnormalities meeting criteria for pulmonary rehabilitation, with associated symptoms and functional limitations, should be referred for pulmonary rehabilitation, whenever possible.</li> </ul> </li> <li>▪ Provide breathing exercises through self-directed educational resources, in-person rehabilitation, or online.</li> <li>▪ For patients with breathing discomfort that is slowly improving after COVID-19, or for those without access to supervised rehabilitation, provide information on self-monitored paced physical activity and breathing therapies. For patients with phone-based or wearable activity trackers, use data to track progress of therapy.</li> <li>▪ Instruct patients with chronic productive cough, difficulty clearing airway secretions, or with existing or new evidence of bronchiectasis regarding airway clearance techniques and consider prescribing an airway clearance device, where appropriate.</li> <li>▪ Pharmacologic therapies, including oral corticosteroids, inhaled bronchodilators, and inhaled corticosteroids, are not routinely recommended for breathing discomfort in the absence of impaired pulmonary function. Treatments may be considered when supported by objective findings (e.g., examination, diagnostics). Consultation with a pulmonologist may be considered to assist this decision.</li> </ul> |
| <b>Service planning</b>                                    |  |
| <b>Recommendations for service planning for long COVID</b> | N/R  |

**Key:** N/A - not applicable; N/R – not reported; PASC – post acute sequelae of SARS-CoV-2; PFTs - pulmonary function tests.

## Appendix 4.6 Data extraction table for multi-disciplinary collaborative consensus guidance statement on the assessment and treatment of cognitive symptoms in patients with post-acute sequelae of SARS-CoV-2 infection

| Clinical guideline and or model of care characteristics  |   |
|--|---|
| <b>Endorsing Organisation</b>  | American Academy of Physical Medicine and Rehabilitation Multi-Disciplinary Post-acute Sequelae of SARS-CoV-2 (PASC) Collaborative  |
| <b>Title</b>   | Multi-disciplinary collaborative consensus guidance statement on the assessment and treatment of cognitive symptoms in patients with PASC   |
| <b>Country</b>   | US  |
| <b>Date Published</b>  | 13 December 2021  |
| <b>URL</b>   | <a href="https://doi.org/10.1002/pmjr.12745">https://doi.org/10.1002/pmjr.12745</a>   |
| <b>National or regional</b>  | National  |
| <b>Adapted from previous guidelines and or model of care?<br/>If so which guidelines and or model of care was it adapted from?</b> | N/A   |
| <b>Update(s) planned (including dates)</b>   | The PASC Collaborative will be polled every 3 months following the release of each guidance statement to determine if revisions are needed to align with current practice.  |
| Definition and diagnosis   |   |
| <b>Specific long COVID sequelae referred to</b>  | Cognitive Symptoms  |
| <b>Definition of long COVID used in the guideline and or model of care</b>   | <b>PASC</b><br>Symptoms that do not improve 1 month after acute COVID-19 symptom onset.   |
| <b>Recommendations for diagnosis of long COVID</b>   | <b>Symptoms</b> <ul style="list-style-type: none"> <li>▪ Common neurological and neuropsychiatric symptoms in individuals with PASC include: <ul style="list-style-type: none"> <li>○ fatigue</li> <li>○ myalgia</li> <li>○ headaches</li> <li>○ sleep disturbance</li> <li>○ anxiety</li> <li>○ depression</li> <li>○ dizziness</li> </ul> </li> </ul> |

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|  | <ul style="list-style-type: none"> <li>○ anosmia</li> <li>○ dysgeusia</li> <li>○ cognitive symptoms, often called a “brain fog”. Primary cognitive symptoms include deficits in reasoning, problem solving, spatial planning, working memory, difficulty with word retrieval, and poor attention.</li> </ul> <p><b>PASC cognitive symptom assessment recommendations</b></p> <ul style="list-style-type: none"> <li>■ Patients should be screened for signs of cognitive symptoms using validated tools and instruments. Commonly used cognitive screening tools include: <ul style="list-style-type: none"> <li>○ montreal Cognitive Assessment</li> <li>○ mini-Mental State Examination</li> <li>○ saint Louis University Mental Status Examination</li> <li>○ mini-Cog, Short Test of Mental Status</li> </ul> </li> <li>■ Patients should be evaluated for conditions that may exacerbate cognitive symptoms and warrant further testing and potential subspecialty referral. Particular areas include: <ul style="list-style-type: none"> <li>○ sleep impairment</li> <li>○ mood, including anxiety, depression, and posttraumatic stress disorder</li> <li>○ fatigue</li> <li>○ endocrine abnormalities</li> <li>○ autoimmune disorders</li> <li>○ Note: Patients often report dissatisfaction with their care because of their persistent symptoms being attributed to psychological factors. It is important to note that mood disorders may be secondary to persistent medical conditions or one of many factors leading to cognitive symptoms.</li> </ul> </li> <li>■ Patients should have a thorough neurological examination to identify focal neurological deficits.</li> <li>■ For those patients identified with new or worsening focal neurological deficits (including new or worsening cognitive symptoms) an emergent evaluation is warranted; neuroimaging should be considered.</li> <li>■ The following basic lab workup should be considered to screen for reversible factors contributing to cognitive symptoms. The initial lab workup in new patients or those without lab workup in the 3 months prior to visit including complete blood count, vitamin B12, thiamine, folate, homocysteine, 1,25-dihydroxy vitamin D, magnesium, liver function tests, comprehensive metabolic panel thyroid function tests (thyroid stimulating hormone, free T3, free T4). In high-risk patients, one may consider syphilis rapid plasma regain and human immunodeficiency virus testing. <ul style="list-style-type: none"> <li>○ Other laboratory tests may be considered based on the results of these tests or if there is specific concern for comorbid conditions.</li> </ul> </li> <li>■ Clinicians should conduct a full patient history with review of preexisting conditions and comprehensive medication and supplement review for those that may contribute to cognitive symptoms.</li> </ul> |
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|  | <ul style="list-style-type: none"> <li>○ Of note, patients with PASC often present on antihistamine, anticholinergic, and antidepressant/ anxiolytic medications that can contribute to cognitive symptoms.</li> <li>▪ Clinicians should validate patient history through the collection of collateral history, including preexisting function and conditions, from care team/primary care, patient family or care partner, or close contact as available. <ul style="list-style-type: none"> <li>○ Clinicians should assess impact of cognitive symptoms using standardised patient-reported assessments, to include activities of daily living, instrumental activities of daily living, school, work and avocational (i.e. hobbies), and quality of life.</li> </ul> </li> </ul>   |
| <b>Management and treatment</b>                                      |   |
| <b>Recommendations for treatment and or management of long COVID</b> | <p><b>PASC cognitive symptom treatment recommendations</b></p> <ul style="list-style-type: none"> <li>▪ For patients who screen positive for cognitive symptoms, refer to a specialist (i.e. speech-language pathologist, occupational therapist, neuropsychologist) with expertise in formal cognitive assessment and remediation.</li> <li>▪ Treat, in collaboration with appropriate specialists, underlying medical conditions, such as pain, insomnia/sleep disorders (including poor sleep hygiene), and mood disorders that may be contributing to cognitive symptoms.</li> <li>▪ Complete, in collaboration with patient primary care provider, medication polypharmacy reduction, weaning or deprescribing medications if medically feasible with emphasis on medications that may impact cognition.</li> <li>▪ Reinforce sleep hygiene techniques including nonpharmacologic approaches as first line of sleep remediation.</li> <li>▪ Similar to patients experiencing “physical” fatigue, patients should be advised to begin an individualized and structured, titrated return to activity program.</li> <li>▪ For patients who achieve a return to their normal, daily activities, regular exercise (at least 2–3 times/week of aerobic exercise) may be effective in improving cognition and also contribute to improved sleep patterns.</li> <li>▪ Frequent assessment of the impact of return to normal, daily activities (including school, work, driving, operating heavy machinery, etc.) is recommended to ensure that symptoms do not flare and exercise is tolerated.</li> </ul> |
| <b>Service planning</b>  |   |
| <b>Recommendations for service planning for long COVID</b>           | N/R   |

**Key:** N/A - not applicable; N/R – not reported; PASC – post acute sequelae of SARS-CoV-2.

### Appendix 4.7 Data extraction table for 2022 ACC Expert Consensus Decision Pathway on Cardiovascular Sequelae of COVID-19 in Adults: Myocarditis and Other Myocardial Involvement, Post-Acute Sequelae of SARS-CoV-2 Infection, and Return to Play

| Clinical guideline and or model of care characteristics  |  |
|--|--|
| <b>Endorsing Organisation</b>  | The American College of Cardiology   |
| <b>Title</b>   | 2022 ACC Expert Consensus Decision Pathway on Cardiovascular Sequelae of COVID-19 in Adults: Myocarditis and Other Myocardial Involvement, PASC Infection, and Return to Play  |
| <b>Country</b>   | US   |
| <b>Date Published</b>  | 3 May 2022   |
| <b>URL</b>   | <a href="https://doi.org/10.1016/j.jacc.2022.02.003">https://doi.org/10.1016/j.jacc.2022.02.003</a>  |
| <b>National or regional</b>  | National   |
| <b>Adapted from previous guidelines and or model of care?<br/>If so which guidelines and or model of care was it adapted from?</b> | N/A  |
| <b>Update(s) planned (including dates)</b>   | N/R  |
| Definition and diagnosis   |  |
| <b>Specific long COVID sequelae referred to</b>  | Cardiovascular   |
| <b>Definition of long COVID used in the guideline and or model of care</b>   | <p><b>PASC</b></p> <ul style="list-style-type: none"> <li>Condition defined by a constellation of symptoms that emerge or persist after recovery from COVID-19, usually lasting for 4-12 weeks and beyond.</li> </ul> <p><b>PASC-CVD</b></p> <ul style="list-style-type: none"> <li>Refers to a broad group of cardiovascular conditions that manifest <math>\geq 4</math> weeks after SARS-CoV-2 infection. Timing, however, may vary depending upon initial illness severity. PASC-CVD includes, but is not limited to, myocarditis and other forms of myocardial involvement, pericarditis, new or worsening myocardial ischemia due to obstructive coronary artery disease, microvascular dysfunction, nonischemic cardiomyopathy with involvement of the left and/or right ventricles, thromboembolism, cardiovascular sequelae of pulmonary disease (eg, pulmonary hypertension, right ventricular failure), and arrhythmia (eg, atrial fibrillation, premature ventricular contractions, nonsustained ventricular tachycardia).</li> </ul> <p><b>PASC-CVS</b></p> |



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|  | <ul style="list-style-type: none"> <li>Is a heterogeneous disorder that includes widely ranging cardiovascular symptoms, without objective evidence of cardiovascular disease using standard diagnostic tests. Exercise intolerance and tachycardia are 2 of the most common reported symptoms; others include chest pain and dyspnea, with or without exercise intolerance. Additional accompanying symptoms include fatigue; cognitive complaints, including memory impairment, attention deficit, and poor executive function (frequently described as brain fog); sleep disturbance or nonrestorative sleep; and postexertional malaise.</li> </ul>   |
| <b>Recommendations for diagnosis of long COVID</b>                   | <p><b>For patients with cardiovascular symptoms and suspected PASC, a reasonable initial testing approach includes:</b></p> <ul style="list-style-type: none"> <li>Basic laboratory testing (including cardiac troponin)</li> <li>An electrocardiogram</li> <li>An echocardiogram</li> <li>An ambulatory rhythm monitor</li> <li>Chest imaging (X-ray and/or CT)</li> <li>Pulmonary function tests</li> </ul> <p><b>Cardiology consultation is recommended for patients with PASC that have:</b></p> <ul style="list-style-type: none"> <li>Abnormal cardiac test results</li> <li>Known cardiovascular disease with new or worsening symptoms or signs</li> <li>Documented cardiac complications during SARS-CoV- 2 infection</li> </ul> <p>and/or</p> <ul style="list-style-type: none"> <li>Persistent cardiopulmonary symptoms that are not otherwise explained</li> </ul>                          |
| <b>Management and treatment</b>                                      |   |
| <b>Recommendations for treatment and or management of long COVID</b> | <p><b>Exercise</b></p> <ul style="list-style-type: none"> <li>Recumbent or semi-recumbent exercise (eg, rowing, swimming, or cycling) is recommended initially for PASC-CVS patients with tachycardia, exercise/orthostatic intolerance, and/or deconditioning, with transition to upright exercise as orthostatic intolerance improves.</li> <li>Exercise duration should also be short (5-10 minutes/day) initially, with gradual increases as functional capacity improves.</li> </ul> <p><b>Treatment</b></p> <ul style="list-style-type: none"> <li>Salt and fluid loading represent nonpharmacological interventions that may provide symptomatic relief for patients with tachycardia, palpitations, and/or orthostatic hypotension.</li> <li>Beta-blockers, nondihydropyridine calcium-channel blockers, ivabradine, fludrocortisone, and midodrine may be used empirically as well.</li> </ul> |
| <b>Service planning</b>  |   |
| <b>Recommendations for service planning for long COVID</b>           | N/R   |

**Key:** CT - computed tomography; CVD - cardiovascular disease; CVS - cardiovascular syndrome; N/A - not applicable; N/R – not reported; PASC - post-acute sequelae of SARS-CoV-2.

## Appendix 4.8 Data extraction table for Multi-disciplinary collaborative consensus guidance statement on the assessment and treatment of cardiovascular complications in patients with post-acute sequelae of SARS-CoV-2 infection

| Clinical guideline and or model of care characteristics  |   |
|--|---|
| <b>Endorsing Organisation</b>  | American Academy of Physical Medicine and Rehabilitation Multi-Disciplinary Post-acute Sequelae of SARS-CoV-2 (PASC) Collaborative  |
| <b>Title</b>   | Multi-disciplinary collaborative consensus guidance statement on the assessment and treatment of cardiovascular complications in patients with PASC   |
| <b>Country</b>   | US  |
| <b>Date Published</b>  | 7 June 2022   |
| <b>URL</b>   | <a href="https://doi.org/10.1002%2Fpmrj.12859">https://doi.org/10.1002%2Fpmrj.12859</a>   |
| <b>National or regional</b>  | National  |
| <b>Adapted from previous guidelines and or model of care?<br/>If so which guidelines and or model of care was it adapted from?</b> | N/A   |
| <b>Update(s) planned (including dates)</b>   | The PASC Collaborative will be polled every 3 months following the release of each guidance statement to determine if revisions are needed to align with current practice.  |
| Definition and diagnosis   |   |
| <b>Specific long COVID sequelae referred to</b>  | Cardiovascular complications  |
| <b>Definition of long COVID used in the guideline and or model of care</b>   | <p><b>PASC</b></p> <ul style="list-style-type: none"> <li>▪ Symptoms that do not improve 1 month after acute COVID-19 symptom onset.</li> </ul>   |
| <b>Recommendations for diagnosis of long COVID</b>   | <p><b>Symptoms of cardiovascular complications</b></p> <ul style="list-style-type: none"> <li>▪ In general, individuals with PASC-related cardiovascular disease may present with symptoms including: <ul style="list-style-type: none"> <li>○ Shortness of breath</li> <li>○ Fatigue</li> <li>○ Chest pain</li> <li>○ Palpitations</li> <li>○ Dizziness</li> <li>○ Abdominal bloating</li> <li>○ Leg swelling</li> </ul> </li> </ul> |

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|  | <ul style="list-style-type: none"> <li>○ Impaired activity tolerance <ul style="list-style-type: none"> <li>▪ In individuals with coexistent PASC-related autonomic dysfunction, related symptoms may significantly overlap with those of heart disease.</li> </ul> </li> </ul> <p><b>Types of cardiovascular complications in PASC</b></p> <p>The reported incidence of cardiovascular complications due to acute COVID-19 disease includes:</p> <ul style="list-style-type: none"> <li>▪ Myocardial injury: 7%–40% (MI; transient myocardial ischemia; acute nonischemic myocardial injury) with a higher prevalence among those requiring intensive care</li> <li>▪ Acute heart failure: 23%–33% among hospitalised patients</li> <li>▪ Right ventricular dysfunction: 16%–35%</li> <li>▪ Right ventricular dilation: 12%–15%</li> <li>▪ Arrhythmias: 18% (atrial fibrillation/flutter most common) <ul style="list-style-type: none"> <li>○ 4%–6% are life-threatening arrhythmias (ventricular tachycardia/ventricular fibrillation) and more common in those with elevated cardiac troponins</li> </ul> </li> <li>▪ Venous thromboembolism: 15%–21% in hospitalised patients</li> </ul> <p><b>PASC cardiac complications assessment recommendations</b></p> <ul style="list-style-type: none"> <li>▪ Patient History: A full patient history should be performed to include review of predisposing comorbidities, prior cardiovascular events, severity of the initial COVID-19 illness—mild, moderate, severe, including relevant hospitalisation and care in ICU, need for ventilator, extra-corporeal membrane oxygenation etc., and timeline of symptom evolution. <ul style="list-style-type: none"> <li>○ Additional components of the patient history should address: <ul style="list-style-type: none"> <li>▪ Most common new or worsening cardiac symptoms: chest pain, palpitations, shortness of breath, near-or syncopal episodes, exercise intolerance, fatigue.</li> <li>▪ Studies conducted to date: labs, electrocardiogram, echocardiogram, chest imaging, other cardiac work-up if done (cardiac catheterization, cardiac magnetic resonance imaging, etc.).</li> <li>▪ Medication history—Evaluate for medications that may impact symptoms, signs or assessment parameters (ie, medications with antiarrhythmic, diuretic or vaso-active impact).</li> </ul> </li> </ul> </li> <li>▪ Patient History: Symptoms should be characterised to understand contributing factors that limit activity including onset (new, acute or chronic), frequency, intensity, aggravating and alleviating factors, etc.</li> <li>▪ Initial Evaluation: Clinicians should conduct a thorough examination of the cardiovascular system including routine vital signs (heart rate, blood pressure, pulse oximetry), auscultation of heart and lungs, peripheral pulses and bruits, and signs of volume overload.</li> <li>▪ Initial Evaluation: For individuals reporting dizziness, lightheadedness, and syncope/presyncope clinicians should further characterize the perceived dizziness (lightheadedness vs. room spinning sensation) and differentiate between central or peripheral etiologies which warrant specialist referral.</li> <li>▪ Initial Evaluation: To differentiate cardiovascular from autonomic dysfunction, check for orthostatic blood pressure and heart rate response in supine and standing position. If abnormal or symptoms are concerning</li> </ul> |
|--|--|

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|   | <p>for autonomic dysfunction, continue evaluation as per the autonomic dysfunction guideline including a 10-min active stand test.</p> <ul style="list-style-type: none"> <li>▪ Order basic laboratory work-up in individuals with cardiac symptoms, or those without lab work-up in the 3 months prior to the visit. Consider: complete blood count, basic metabolic panel, troponin level (preferably high-sensitivity), brain natriuretic peptide or N-terminal pro b-type natriuretic peptide, D-dimer, C-reactive protein and erythrocyte sedimentation rate, lipid panel. Further laboratory work-up may be considered based on the results of the basic tests or if there is concern for specific cardiac conditions.</li> <li>▪ Clinicians should consider ordering electrocardiogram, echocardiogram, and/or ambulatory cardiac monitoring.             <ul style="list-style-type: none"> <li>○ Holter for symptoms occurring every day.</li> <li>○ 14-day monitor (e.g., Ziopatch) for symptoms occurring every few days.</li> <li>○ Event monitor (looping or non-looping, mobile cardiac telemetry) for infrequent symptoms.</li> </ul> </li> <li>▪ Where diagnosis is uncertain or symptoms are progressing or severe consider referral to a cardiologist for more detailed assessment (computed tomography of the chest, cardiac magnetic resonance imaging, cardiac stress testing, cardiopulmonary exercise testing).</li> <li>▪ On initial evaluation, obtain standardised measures of activity performance to compare to normal control values and to guide the initial activity prescription. Repeat the standardised measures of activity performance at follow-up visits to quantify functional changes and guide progression of the activity prescription.</li> <li>▪ Recommendations based on evaluation should be patient-centered and address the goals of the individual.ferentiate between central or peripheral etiologies which warrant specialist referral.</li> <li>▪ Health equity considerations relating to diagnosis are provided.</li> </ul> |
| <b>Management and treatment</b>   |   |
| <p><b>Recommendations for treatment and or management of long COVID</b></p> | <p><b>PASC cardiac complications treatment recommendations</b></p> <ul style="list-style-type: none"> <li>▪ Provide counseling and education for risk factor modification in individuals identified with risk factors for cardiovascular disease, including dyslipidemia, diabetes, hypertension, overweight/obesity, sedentary lifestyle, and depression. Education components can include:             <ul style="list-style-type: none"> <li>○ Lifestyle modifications</li> <li>○ Diet/nutrition</li> <li>○ Activity/exercise</li> <li>○ Medications</li> <li>○ Risk factors</li> <li>○ Disease process</li> <li>○ Reassurance</li> </ul> </li> </ul>  |

|  |   |
|--|---|
|  | <ul style="list-style-type: none"> <li>▪ Evaluate and manage individuals diagnosed with new or worse complex arrhythmias in conjunction with a cardiologist.</li> <li>▪ Evaluate and manage individuals diagnosed with new or worse structural heart disease in conjunction with a cardiologist.</li> <li>▪ Evaluate and manage individuals diagnosed with new or worsened coronary heart disease in conjunction with a cardiologist.</li> <li>▪ Evaluate and manage individuals diagnosed with new or worse ventricular dysfunction in conjunction with a cardiologist.</li> <li>▪ Individuals with a recent history of cardiac events and diagnosis that qualifies them for cardiac rehabilitation—myocardial infarction, stable angina, coronary intervention (percutaneous coronary intervention including angioplasty or cardiac stenting), systolic heart failure with ejection fraction <math>\leq</math> 35%, heart surgery such as coronary artery bypass surgery, heart valve repair or replacement, and heart or heart-lung transplant—should be referred for cardiac rehabilitation.</li> <li>▪ Individuals with prior history of athletic performance should be evaluated, counseled, and guided back to sports performance through a staged return to play approach.</li> <li>▪ Health equity considerations relating to diagnosis are provided.</li> </ul> |
| <b>Service planning</b>                                    |   |
| <b>Recommendations for service planning for long COVID</b> | N/R   |

**Key:** ICU - intensive care unit; MI - myocardial injury; N/A - not applicable; N/R – not reported; PASC- post acute sequelae of SARS-CoV-2.

## Appendix 5 AGREE-GRS Quality Appraisal Checklist

| <b>Process of development</b>   |               |  |                 |
|---|---------------|--|-----------------|
| <b>Rate the overall quality of the guideline development methods</b>                      | <b>Yes/No</b> | <b>Score 1-7<br/>(Lowest quality: 1 to Highest quality: 7)</b> | <b>Comments</b> |
| Were the appropriate stakeholders involved in the development of the guideline?           |               |  |                 |
| Was the evidentiary base developed systematically?  |               |  |                 |
| Were recommendations consistent with the literature?                                      |               |  |                 |
| Did the authors describe the explicit link between the evidence and the recommendations?* |               |  |                 |
| When was the guideline last updated? Are there plans for further updates?*                |               |  |                 |
| <b>Presentation style</b>   |               |  |                 |
| <b>Rate the overall quality of the guideline presentation</b>                             | <b>Yes/No</b> | <b>Score 1-7<br/>(Lowest quality: 1 to Highest quality: 7)</b> | <b>Comments</b> |
| Was the guideline well organized?   |               |  |                 |
| Were the recommendations easy to find?  |               |  |                 |
| <b>Completeness of reporting</b>  |               |  |                 |
| <b>Rate the completeness of reporting</b>   | <b>Yes/No</b> | <b>Score 1-7<br/>(Lowest quality: 1 to Highest quality: 7)</b> | <b>Comments</b> |
| Was the guideline development process transparent and reproducible?                       |               |  |                 |
| Were conflicts of interest recorded?*   |               |  |                 |
| How complete was the information to inform decision-making?                               |               |  |                 |
| Was a decision-making framework used?*  |               |  |                 |
| <b>Clinical validity</b>  |               |  |                 |
| <b>Rate the overall quality of the guideline recommendations</b>                          | <b>Yes/No</b> | <b>Score 1-7<br/>(Lowest quality: 1 to Highest quality: 7)</b> | <b>Comments</b> |
| Are the recommendations clinically sound?   |               |  |                 |

|   |              |  |                 |
|---|--------------|--|-----------------|
| Did the authors report the benefits, side effects risks that were considered when formulating the recommendations?*   |              |  |                 |
| Were the recommendations reviewed externally?*  |              |  |                 |
| Are the recommendations current (i.e. were the evidence sources underpinning the recommendations updated)?*   |              |  |                 |
| Are the recommendations appropriate for the intended patients?  |              |  |                 |
| Was the evidence drawn from the correct population? Did the authors report the criteria used to select the evidence (i.e. inclusion/exclusion criteria such as population, disease stage)?* |              |  |                 |
| <b>OVERALL ASSESSMENT</b>   | <b>Score</b> |  | <b>Comments</b> |
| Rate the overall quality of this guideline<br><i>Score 1-7</i><br><i>(Lowest quality: 1 to Highest quality: 7)</i>  |              |  |                 |
| I would recommend this guideline for use in practice<br><i>Score 1-7</i><br><i>(Strongly disagree: 1 to Strongly agree: 7)</i>  |              |  |                 |
| I would make use of a guideline of this quality in my professional decisions<br><i>Score 1-7</i><br><i>(Strongly disagree: 1 to Strongly agree: 7)</i>                                      |              |  |                 |

\*additional considerations to aid in the quality appraisal process



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