



PRACTICE POINTER

Long covid—an update for primary care

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What you need to know

- Long covid (prolonged symptoms following covid-19 infection) is common
- The mainstay of management is supportive, holistic care, symptom control, and detection of treatable complications
- Many patients can be supported effectively in primary care by a GP with a special interest

This article updates and extends a previous *BMJ* Practice Pointer published in August 2020 when almost no peer reviewed research or evidence based guidance on the condition was available.¹ In this update we outline how clinicians might respond to the questions that patients ask.

Definition

The term “long covid”² refers to prolonged symptoms following infection with SARS-CoV-2 that are not explained by an alternative diagnosis. It embraces the National Institute for Health and Care Excellence (NICE)’s terms “ongoing symptomatic covid-19” (symptoms lasting 4-12 weeks) and “post covid-19 syndrome” (symptoms beyond 12 weeks),³ the US Centers for Disease Control and Prevention’s group of “post-covid conditions,”⁴ and the World Health Organization’s “post covid-19 condition.”⁵

Epidemiology

In mid-2022, approximately 70% of the UK adult population had been infected with SARS-CoV-2.⁶ Of these, almost 2 million report covid-19 symptoms persisting for more than four weeks; 807 000 (41% of all people with long covid) for more than a year; and 403 000 (19%) for more than two years.⁷ Based on workforce data from the British Medical Association,⁸ a full time equivalent general practitioner with an average list size (approximately

2000) has around 65 patients with long covid, 27 of whom will have been unwell for more than a year, and 12 for more than two years. Most general practices have far fewer patients with a long covid diagnostic code on their electronic health record⁹ for a combination of reasons, including lack of presentation, lack of recognition, and inadequate coding. These figures do not cover children, who are outside the scope of this article.

Rates of long covid are lower in people who are triple vaccinated, but prevalence of long covid (persistent symptoms at 12-16 weeks after laboratory confirmed SARS-CoV-2 infection) remains high at 5% for the delta variant and 4.2% for omicron BA.2.¹⁰

Symptoms and case definition

Long covid may be diagnosed late or not at all,¹¹⁻¹³ so both generalists and specialists should be alert to it as a differential, while also being aware that patients can develop other persistent symptoms following acute covid-19 that are not necessarily caused by covid-19. Long covid is characterised by a constellation of general and organ specific symptoms, the commonest of which are summarised in the infographic. These multiple manifestations lead to difficulties with daily activities such as washing and dressing, low exercise tolerance, and impaired ability to work (either at all or partially), and result in reduced quality of life.^{5 14-19}

Symptoms typically occur across multiple systems concurrently but sometimes one organ system (eg, cardiovascular) dominates. Phenotyping studies have identified several symptom clusters (table 1), with severe cases characterised by greater number and intensity of symptoms and greater functional impairment.³³⁻³⁵ Some patients’ long covid follows a fairly constant course, while others experience relapsing and remitting symptoms, sometimes with particular triggers.³⁶

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Table 1 | Symptoms, investigation, and management of long covid

Symptom cluster	Description and impact on daily life	Investigations (in addition to full clinical examination)	Management
Fatigue, low exercise tolerance, deconditioning (eg, post-ICU)	"Battery flat," unable to do usual activities. Trying to do more may worsen symptoms. In some cases, fatigue does not improve with rest	Bloods as appropriate (eg, full blood count, urea and electrolytes, renal, thyroid, vitamin D, C reactive protein, B12, ferritin). Exclude other causes of fatigue. Monitor symptom severity and frequency and pattern of relapses (eg, using the C19-YRS outcome measure). Consider autonomic dysfunction (see below)	Holistic management is key. Self-management to function within available energy limits (eg, prioritising, planning, building in breaks and rests, knowing when to stop ²⁰). Signpost to resources (see box, Resources for patients)
Post-exertional symptom exacerbation (PESE)	"Crash," "relapse" worsening of symptoms (physical, cognitive, or emotional), or new symptoms, following exertion	Monitor symptom severity and frequency and pattern of relapses (eg, using C19-YRS). A patient activity diary can record triggers (for relapse)	Signpost to resources. Pacing in phases (see WHO self-management booklet, box, Resources for patients)
Exertional breathlessness	Short of breath predominantly with physical activity	Guided by specific symptoms. Assess impact on function (eg, using item 1 of C19-YRS). Haemoglobin, spirometry, full lung function tests as indicated. Natriuretic peptides and echocardiogram as indicated if heart failure suspected. Pulse oximetry and sit-to-stand test for exertional hypoxia. ²¹ Chest x ray image (especially if patient was hospitalised) if persistent lung damage suspected and to exclude other causes. ²² D dimer if acute pulmonary embolism suspected (note that a negative result does not exclude chronic pulmonary emboli ²³)	Refer according to clinical concern (eg, worsening symptoms, resting or exertional hypoxia, unexplained abnormal spirometry, abnormal chest x ray image)
Altered breathing/breathing pattern disorder	Pressure in chest ("covid squeeze"), shallow breathing, breathlessness with or without exertion, sense of needing to work harder to take a breath, or air hunger ("can't get enough air")	Exclude other causes of breathlessness as listed above, especially causes of episodic breathlessness such as asthma or recurrent pulmonary embolism	Recommend breathing control exercises, signpost to online resources for breathing pattern disorder (box, Resources for patients), and if no improvement refer to specialist
Chest pain	Pain in specific positions, pain on exertion, "lung burn," pressure ("like an elephant sitting on my chest")	Guided by specific symptoms. Chest pain may indicate microvascular angina, myocardial infarction, myo- or pericarditis, pulmonary embolism or costochondritis. ECG, troponin, D dimer, oximetry (including sit-to-stand test), vitamin D, imaging as indicated	Chest pain with angina-like features warrants referral to a rapid access chest pain clinic. Consider colchicine or anti-inflammatory analgesics for inflammatory type pain once other causes excluded
Throat and voice symptoms	"Covid strangle"—sore or dry throat with sensation of choking; altered voice	Full history and assessment to explore differential diagnosis (eg, covid related vocal cord pathology, gastro-oesophageal reflux, sinus disease, strained voice, dehydration)	If not improving, refer to ear, nose, and throat or speech and language therapist as appropriate
Autonomic dysfunction	Palpitations, dizziness, orthostatic tachycardia, gastro-intestinal disturbance, generalised pain	NASA 10-minute lean test to check for postural orthostatic tachycardia syndrome (POTS) ²⁴ (protocol in supplementary file). ²⁵ Investigations for other causes of autonomic dysfunction/POTS if positive. 24 hour ECG and blood pressure	Fluids, electrolytes, compression garments, lifestyle adaptation, and specialist rehabilitation if tolerated. Various drugs are under investigation. ²⁶ Specialist referral if symptoms severe or diagnosis in doubt
Neurocognitive dysfunction	"Brain fog" (poor short term memory, concentration, problem solving, and executive function). Mental fatigue	Brief cognitive screening test (eg, mini mental state examination ²⁷). Fatigue investigations as above. If memory loss pre-dated covid-19 and is now worsening, follow usual investigations and pathway	Strategies of pacing and energy conservation, to-do list diary, avoid multitasking. If unable to work or have a safety critical occupation, refer for formal neuropsychological testing
Dizziness and vertigo	Unpleasant episodes, "room spinning," nausea	Full history to identify timing and triggers and ascertain if resolving. Clinical examination (eg, nystagmus, other neurological signs, postural drop in blood pressure)	Precautionary measures to avoid falls, head tilt and balance exercises, encouraging movement and activity focusing on environmental cues. Refer to audiology if indicated
Loss of smell	Loss of enjoyment of food and mealtimes. Phantosmia (a persistent, disagreeable background smell) or parosmia (distorted sense of smell) ²⁸	Clinical examination to exclude nasal polyps, chronic sinusitis, and rare inflammatory or neoplastic conditions of nasal cavity and cranial nerves	Smell training (see box, Resources for patients). Experiment with different foods and menus to find palatable options. Steroid nasal spray may help in some cases
Allergic-type symptoms	Skin rashes (eg, urticaria), conjunctivitis, abdominal bloating, regurgitation	Confirm urticaria clinically (eg, dermatographism). If present, may indicate mast cell overactivity. Resurgent atopy (eg, hay fever recurring after many years) is common post covid	Antihistamines (obtainable over the counter) may help. A clinical trial of specific antihistamines is underway (STIMULATE-ICP). ²⁹ Allergy or immunology referral if fulfils local criteria (eg, anaphylaxis)

Table 1 | Symptoms, investigation, and management of long covid (Continued)

Symptom cluster	Description and impact on daily life	Investigations (in addition to full clinical examination)	Management
Poor sleep	Unrefreshing sleep, exhaustion, exacerbation of fatigue and brain fog, vivid dreams or nightmares	Assess daytime somnolence (eg, using Epworth sleepiness scale ³⁰); exclude underlying causes (eg, obstructive sleep apnoea using STOP-Bang questionnaire ³¹). Assess psychological health. Covid related sleep disorder often overlaps with autonomic dysfunction and mast cell disorder	Sleep hygiene measures (eg, structured routines, exercise as able, avoid shift work if possible, avoid caffeine and alcohol), short daytime naps. Melatonin may help restore circadian rhythms in some cases (exclude other causes before prescribing) ³²
Mental health	Anxiety, depression, post-traumatic stress disorder (PTSD). Loss of identity and purpose	Full history (hear the patient's story; witness their experience; affirm their lived experience). Carefully distinguish anxiety from POTS (see above). Assess risk of self-harm and risk to any dependents	Whole person care. Adjusting to illness. Talking therapy, meditation, and medication if indicated. Mental health referral or social prescribing if appropriate
Joint and muscle pain	Generalised, focal, or regional pain. May be in "coat hanger" distribution. May progress to chronic pain	Investigations guided by history and clinical examination. C reactive protein (if inflammatory disorder suspected), creatine kinase (if myositis suspected). Additional tests as indicated for rheumatological disorders	Non-steroidal anti-inflammatory drugs. Mobilisation within personal limits. Consider trial of neuropathic agents (amitriptyline, gabapentin, pregabalin) in chronic cases, especially if neuropathic symptoms

Fatigue—described by one patient as “like the most severe jet lag and hangover I’ve ever had”³⁷—is the commonest symptom and may be associated with severe functional impairment; reduced exercise tolerance is also common. Some patients develop post-exertional malaise (PEM) or post-exertional symptom exacerbation (PESE),¹¹ defined as worsening of symptoms following physical or mental exertion, typically 12 to 48 hours after activity and lasting days or (rarely) weeks.³⁸ Long covid has evident (but under-researched) overlaps with chronic fatigue and myalgic encephalomyelitis.³⁹ Box 1 gives examples of patients’ accounts.

Box 1: Patients’ accounts of long covid symptoms and accessing services, from research interviews with people with long covid^{13 40 41}

“I had an odd rash for quite a while; it kept coming and going ... very itchy cough ... very mild asthma ... I started getting the odd headache again Pins and needles, feet going completely numb ... all sorts of odd symptoms, I just kept putting it down to grief until a couple of months in, a friend said, ‘Look, do you think this could be covid?’”

“The fatigue is literally like hitting a wall. I can’t stay awake any more. It’s just like, wow, I have to go to bed.”

“I’d had 11 days of feeling great. And after [a particular] weekend I crashed again. And again it seemed to last for weeks of having these waves of symptoms: shortness of breath, diarrhoea, muscle aches, complete fatigue.”

“I think it [consultation with general practitioner] was a really positive experience and I felt really listened to, and she was able to be honest at that point and said I don’t really know what I can do to help you but you can phone me or email me at any point.”

“My last interaction with my GP was in June. I asked about my lungs, and he said, ‘What do you want me to do about it? You tell me. I have no idea.’ It felt very dismissive [...]. ‘Nothing’s got any evidence so, yeah sorry, I can’t help.’ I went back to work after five weeks still very unwell because nobody believed in long covid in May, they just didn’t believe it.”

Questions patients ask

Why did I get long covid, and what caused it?

Symptoms (especially fatigue) may persist after many infectious illnesses, including other coronaviruses such as SARS and MERS.⁴² But no clear explanation exists for why a particular individual develops long covid while another recovers quickly.

Long covid is more common in those who had more severe acute disease⁴³ but may occur after mild or even asymptomatic

disease.^{34 44} It is more common in people who were hospitalised, aged 35 to 69, female, living in deprived areas, working in healthcare, social care, or education, with high body mass index, and with more than one pre-existing, activity limiting health condition.^{7 34 44 -46}

The underlying cause of long covid is not fully known, but several interacting mechanisms likely contribute.⁴⁷⁻⁴⁹ A chronic, low grade inflammatory response is correlated with the severity of ongoing symptoms in patients who were hospitalised.³³ Some patients have evidence of multi-organ microvascular disease characterised by immunothrombosis and endothelial dysfunction,^{47 48} and some show an autoimmune response, where the body starts to recognise its own tissues and organs as foreign.⁵⁰ Some patients have covid induced neurological damage, particularly to the autonomic nervous system, which controls involuntary functions like heart rate.^{35 46 51} Being chronically ill and with unpredictable relapses may lead to loss of work, income, and social interaction, which in turn can lead to poor mental health.¹⁴ Structural inequalities such as poverty, overcrowding, poor working conditions, and inability to access services are important in the development and course of covid-19 and may form an important context for long covid.⁵²⁻⁵⁴

What can my primary care team do for me?

Patients with long covid greatly value input from their primary care clinician. Notwithstanding prevailing uncertainties and the lack of definitive curative therapies, generalist clinicians can help patients considerably by

- Hearing the patient’s story and validating their experience
- Making the diagnosis of long covid (which does not have to be by exclusion) and excluding alternative diagnoses
- Providing holistic, relationship based care through continuity of care with a sympathetic clinician who knows the patient
- Conducting a full examination in a face-to-face appointment
- Encouraging self-management and directing to resources (box, Resources for patients)
- Managing specific symptoms (table 1)
- Detecting and actioning “red flag” symptoms (infographic)

- Managing comorbidities (especially diabetes and cardiovascular disease and risk factors)
- Sharing the uncertainties of prognosis
- Helping set realistic goals for recovery (including pacing to avoid PESE)
- Considering referral to other members of the primary care team (eg, pharmacist, advanced clinical practitioner, community physiotherapist) or social support services as appropriate
- Monitoring progress
- Assessing mental wellbeing and managing depression and anxiety as needed
- Providing sickness certification
- Supporting self-advocacy (eg, with employer when returning to work)
- Entering the correct code for long covid on the electronic patient record.⁵⁵

All this takes time, and several consultations may be needed.

What investigations should I have?

Long covid affects patients in different ways and to different degrees. Because a key component of care is investigating and managing risk factors and comorbidities, no standard protocol exists for assessment. Ideally, every patient should have an in-person consultation including a full history, clinical examination, and review of comorbidities and social circumstances.

Initial investigations are guided by the predominant symptoms (table 1) and are primarily directed at excluding serious alternative diagnoses. Patients may have heard about tests for immunological and clotting function; such tests are the subject of intense research currently, but they do not yet have an established role in clinical practice.

What treatments are available?

As with investigations, no standard protocol exists for treating long covid. Recovery programmes have been designed and implemented with the aim of improving physical health and mental wellbeing.⁵⁶ The optimal content, delivery method, and duration of these programmes is currently unknown, but under investigation (see EPPICentre resource, box, Resources for healthcare professionals). Programmes to date have been modelled on successful examples such as pulmonary and cardiac rehabilitation, but with substantial modification for adults with long covid who are particularly managing fatigue and PESE.⁵⁷

Much current medication is directed at symptom control (paracetamol or non-steroidal anti-inflammatory drugs for fever and pains, antihistamines for allergic symptoms). Table 1 lists other specific medications for different symptom clusters. Covid vaccines may help long covid symptoms and should be discussed with all those without contraindications who are not already fully vaccinated; they should be told that improvement may be modest and not all patients benefit (indeed, some may experience worsening of symptoms).^{33 58 59}

How will I know if I'm getting better?

The best guide to whether a patient is getting better is whether they feel better (and if they do, whether this reflects permanent recovery or temporary remission). A patient reported outcome measure that measures symptom severity across 10 domains as well as functional

disability and overall health state, known as the Covid-19 Yorkshire Rehabilitation Scale (C19YRS), has been developed and validated (see multimedia appendix).^{60 61} This instrument, which is less burdensome for patient and clinician than multiple condition specific scales, is available in document format (see bmj.com) and as a smartphone app for the patient linked to a web portal for the clinician (<https://c19-yrs.com/>).⁶⁰ It can be completed at intervals over time to chart the patient's recovery (or lack of it).

When will I get better?

The time course of recovery is extremely variable. Approximately two thirds of patients who have persisting symptoms at four weeks can expect to be recovered by 12 weeks.⁴³ Those still unwell at 12 weeks may benefit from specialist multidisciplinary care. They may still improve, albeit at a slower rate, but many patients appear to plateau and their illness course may fluctuate with exacerbations triggered by physical or mental stress.^{7 33 62} It is currently not possible to predict which patients will recover within weeks and which will develop a long term condition.

Do I need to see a specialist?

Many people with long covid can be managed effectively in primary care, but "red flag" symptoms (infographic) require urgent referral and action. Additionally, some patients—those with multiple severe symptoms (especially if both physical and mental health are affected), symptoms persisting after a severe acute illness (eg, a period in intensive care), atypical symptoms, profound functional impairment (eg, unable to work or attend college), and those needing confirmation that self-management or supported rehabilitation is safe and appropriate—benefit from specialist referral.⁶³ Ideally, this should occur in a dedicated "single point of entry" long covid clinic. These integrated clinics spanning primary and secondary care give patients access to additional investigations and other specialists (typically including respiratory medicine, cardiology, neurology, rehabilitation medicine, therapists, and psychologists). Not all localities have such services, and in their absence, a thorough history and clinical assessment should enable a referral to be made to the most appropriate secondary care service. Table 1 and the infographic provide some indicators.

Because health services in many areas are currently very stretched, some patients may experience considerable delays even when their referral meets local criteria. Supportive care and symptom control from the primary care team may be helpful in the interim.

What if I'm not getting better?

Early research on management of post-acute covid-19 assumed (explicitly or implicitly) that patients would recover, albeit slowly. Long covid specialist services in the UK were designed around this assumption and focused on assessment, rehabilitation, occupational therapy, and psychological support. Thirty months into the pandemic, it is clear that this approach helps many but not all patients, and that for a substantial minority, "recovery" currently means developing the ability to manage limited energy, continuing pain, cognitive limitations, and ongoing flare ups in what has become a long term condition.³⁶ In addition to research to characterise persisting forms of long covid and test targeted therapies, models of integrated ongoing care more akin to those for other long term conditions such as diabetes, heart failure, or chronic pain are needed, including evaluating and costing the contribution of primary care to any such service. Community based interdisciplinary services and adequate support and training for healthcare professionals are needed to rapidly improve care and services for the growing numbers of people living with long covid.

Resources for patients

Books

- *The Long Covid Self Help Guide*³⁷—written by specialists at a long covid clinic offering lay explanations and self-management strategies for the different symptom clusters of long covid
- *Support for rehabilitation: self-management after COVID-19 related illness*—a World Health Organization guide for patients²⁰
- *Long Covid Rehabilitation Booklet* from NHS Hertfordshire. <https://www.hct.nhs.uk/media/4529/long-covid-rehabilitation-booklet-july-2021.pdf>.

Websites

- Your Covid Recovery (<https://www.yourcovidrecovery.nhs.uk/>)—an NHS England funded website with public facing resources (Phase I resources). These offer helpful advice for specific symptoms, eg, dizziness (<https://www.yourcovidrecovery.nhs.uk/covid-in-the-last-4-weeks/effects-on-your-body/dizziness/>). Phase II Your Covid Recovery is a web based covid-19 rehabilitation programme with healthcare professional support for those referred into the scheme (usually by a rehabilitation professional)
- Physiotherapy for Breathing Pattern Disorders (<https://www.physiotherapyforbpd.org.uk/>)—a patient facing site designed and run by specialist physiotherapists
- Long Covid Work (<https://longcovidwork.co.uk/>)—a site for people returning to work after long covid.

Support groups

- Long Covid SOS (<https://www.longcovidosos.org>) and Long Covid Support (<https://www.longcovid.org>). Examples of resource and networking sites set up by and for people with long covid.

Resources for healthcare professionals

Guidelines

- Covid-19 rapid guideline: managing the long term effects of covid-19 (by NICE, Royal College of GPs, and Scottish Intercollegiate Guidelines Network)³
- Faculty of Occupational Medicine guidance for health professional on return to work for patients with post-covid syndrome. https://www.fom.ac.uk/wp-content/uploads/FOM-Guidance-post-COVID_healthcare-professionals.pdf
- Society of Occupational Medicine's covid-19 return to work guide for recovering workers. https://www.som.org.uk/COVID-19_return_to_work_guide_for_recovering_workers.pdf
- NICE guideline on chronic pain.

E-learning courses

- Long term effects of covid-19 and post-covid-19 syndrome: an e-learning resource from the UK Royal College of General Practitioners. <https://elearning.rcgp.org.uk/course/view.php?id=492>

- Health Education England long covid e-learning modules for health professionals. <https://www.e-lfh.org.uk/programmes/long-covid/>

Online resources

- Living maps of covid-19 evidence, created by the UCL EPPI-centre, with long covid segment. <http://epi.ioe.ac.uk/cms/Projects/DepartmentofHealthandSocialCare/Publishedreviews/COVID-19Livingssystematicmapoftheevidence/tabid/3765/Default.aspx>
- Living systematic review of long covid, which will be updated as new evidence emerges⁶⁴
- Long covid physio: a resource site intended mainly for physiotherapists and their patients, set up by physiotherapists who have (had) long covid. <https://longcovid.physio>

How patients were involved in the creation of this article

Patients who were members of the LOCOMOTION quality improvement collaborative (see protocol paper for details⁶⁵) contributed the comments in box 1. RM has lived experience of long covid and co-chairs the patient advisory group for LOCOMOTION. The paper was read by three additional patients with long covid and modified in response to their feedback.

We considered patient led and professionally led research on their merits, aware that many high quality studies on this condition were conceptualised and undertaken by patient communities (who included scientists, social scientists and clinicians, who brought relevant research skills as well as lived experience of long covid).

How this article was created

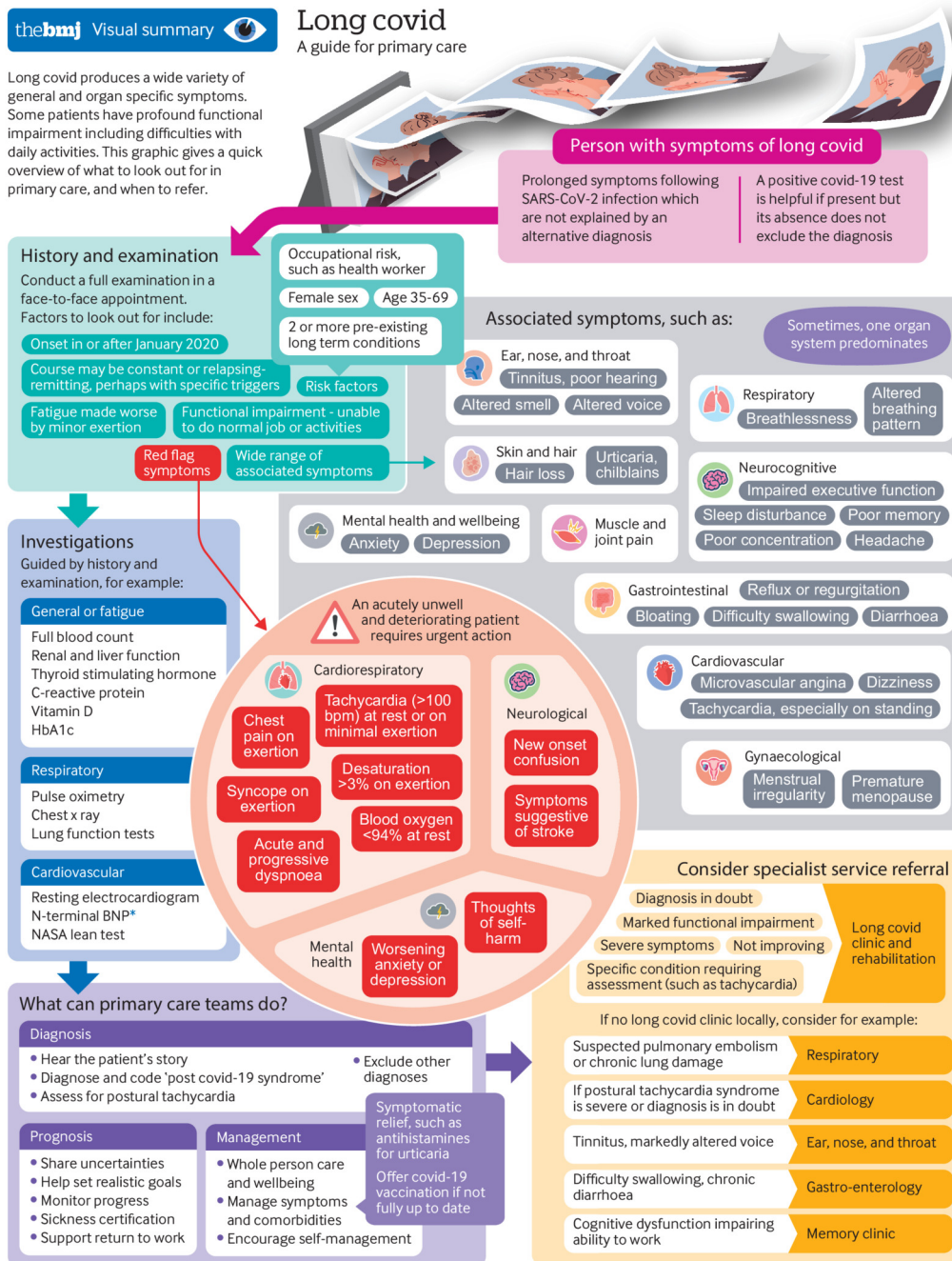
This paper draws on three sources. The first was a literature search of PubMed using the terms “post-acute covid-19 syndrome (MeSH)”, and “long covid (title and abstract)” and including basic science studies and reviews,^{11 47 48 50} narrative reviews, and conceptual papers considering mechanisms,^{14 24 26 36 45 49 52 64 66} clinical trials (of which none had reported at the time of writing), observational studies and reviews of these,^{15 -17 33 34 43 44 46 62 67 -70} systematic reviews of rehabilitation programmes,⁷¹ studies on outcome measures,^{35 60 61 72 -74} social science studies of long covid in vulnerable groups and underserved communities,^{52 -54} surveys^{12 18 75} and a Delphi study⁷⁶ of patient priorities, and qualitative studies of the patient experience.^{2 13 40 41 77} Secondly, the paper drew on group discussions with front line clinicians and patient partners (the LOCOMOTION consortium⁶⁵) who are members of a national quality improvement collaborative for long covid clinics in the UK (these discussions prompted us to undertake further literature searches where needed). Thirdly, we drew on “grey literature” including service specifications,^{78 79} Office of National Statistics publications,^{67 80} guidelines, and policy documents from the UK and internationally,^{3 5 56 57 63 81} and patient facing self-help literature.^{20 37}

thebmj Visual summary

Long covid

A guide for primary care

Long covid produces a wide variety of general and organ specific symptoms. Some patients have profound functional impairment including difficulties with daily activities. This graphic gives a quick overview of what to look out for in primary care, and when to refer.



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* BNP = b-type natriuretic peptide

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Contributorship and guarantor: The paper draws on the clinical experiences and wisdom of the LOCOMOTION consortium. All authors contributed to the literature search and synthesis of key findings from these. TG wrote the first draft, which was extensively amended by other authors. All authors offered feedback on the infographic. All authors read and approved the final manuscript.

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Competing interests: TG is a member of Independent SAGE. MS is WHO Europe adviser on covid rehabilitation policy and led the development of the C19-YRS (Yorkshire Rehabilitation Scale) outcome measure for long covid. RE and TG are members of the NHS England Task Force for long covid.

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