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NICE guideline on long covid

Research must be done urgently to fill the many gaps in this new “living guideline”

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The covid-19 pandemic has killed over 1.6 million people worldwide,¹ caused the worst healthcare crisis of this century, and put a huge dent in our economies. The magnitude of the population still struggling with symptoms four weeks after their acute illness—commonly called “long covid”—is becoming obvious and demands urgent prioritisation to prevent a further blow to health systems and the healthcare workforce.

Long covid is thought to occur in approximately 10% of people infected,^{2,3} so there are likely more than 5 million people affected globally. The National Institute for Health and Care Excellence (NICE), the Scottish Intercollegiate Guidelines Network, and the Royal College of General Practitioners have developed a rapid guideline for managing the long term effects of covid-19⁴ to assist long covid services being set up in the NHS⁵ and elsewhere. A lack of systematic research means that the current guideline is necessarily preliminary, but it will be updated regularly as new evidence emerges—becoming a “living guideline.” This approach is essential as the current guideline lacks important detail, including a comprehensive list of organ complications seen in patients with long covid, the investigations required, and specific interventions for these complications.

Standardised terms

The guideline defines long covid as “signs and symptoms that develop during or following an infection consistent with covid-19 and which continue for more than four weeks and are not explained by an alternative diagnosis.”⁴ Given that we are beginning to understand the underlying immunological and organ specific effects of SARS-CoV-2,^{6,7} it might have been better to define it as “signs and symptoms that continue for more than four weeks and can be attributed to covid-19 infection.” This definition would include all the post-acute medical complications of covid-19 under one unified definition rather than making long covid a vague diagnosis of exclusion.

NICE recommends using the term “post-covid syndrome” from 12 weeks after infection. But no evidence exists of any particular physiological changes (that predict chronicity) at 12 weeks, so it would be preferable to use the term long covid for symptoms of any duration beyond four weeks, as is strongly advocated by people with lived experience of this condition.⁸ Using the prefix “post” implies that acute infection and any active disease process have resolved, which is currently unknown.

Comprehensive assessment

The guideline rightly includes people with suspected covid-19 infection without requiring a positive antigen

or antibody test. Any other approach risks missing the many thousands of people who did not have access to testing in the early phases of the pandemic. The recommendations emphasise comprehensive assessment by a multidisciplinary team and support the use of virtual methods of assessment, including screening questionnaires such as C19-YRS (Yorkshire Rehabilitation Screen).⁹ They also warn clinicians not to rely on questionnaires alone and to undertake additional thorough assessments.

The guidance mentions screening blood tests (such as full blood count; clotting profile; renal, liver, and thyroid functions; and C reactive protein) and tests of both cardiac and lung function to capture reversible abnormalities, but it lacks detail on the management of serious life threatening complications such as a hypercoagulable state.¹⁰ The next update should prioritise how to screen for, diagnose, and manage medical complications¹¹ reported in patients with long covid including silent desaturations; cardiac, respiratory, renal, hepatic, gastrointestinal, and neurological abnormalities; endocrine problems; autonomic dysregulation and postural tachycardia; and mast cell disorder. Missing these complications could result in serious adverse outcomes for patients.

One stop multidisciplinary clinics are recommended, led by a doctor with relevant specialist skills and experience. NHS England has also emphasised the importance of multidisciplinary assessment and diagnostics being available in long covid clinics to avoid multiple referrals to different specialists.⁵ Clearer guidance on the optimal composition of multidisciplinary teams would have been helpful. Respiratory physicians, cardiologists, neurologists, general physicians (from primary care or rehabilitation medicine), neuropsychologists or neuropsychiatrists, physiotherapists, occupational therapists, speech and language therapists, and dieticians may all be required.

Interventions

Shared decision making is appropriately emphasised in the setting of goals and the formulation of personalised management plans and care plans. The guidance lacks detail on potentially helpful rehabilitation interventions such as breathing techniques, psychological interventions (such as cognitive behaviour therapy), cognitive training (such as memory training), and occupational rehabilitation, perhaps understandably given the current paucity of supporting evidence. The dangers of exercise in some patients, such as those with undiagnosed acute pericarditis or myocarditis, highlight the need for a personalised approach.¹² All these aspects of care should be prioritised in future updates.

Research on the underlying pathophysiology of long covid is now urgent, including identifying the immunological, inflammatory, genetic, metabolic, and psychological correlates, to better understand symptom development. The NICE guideline rightly recommends further research to characterise common clusters of symptoms (phenotypes), risk factors, prognostic markers, natural history, and trajectory of long covid, and to identify effective interventions for all age groups.

The need to tackle health inequalities in care for people with long covid—such as those with mental health conditions, learning disabilities, or specific cultural needs, or where there are language barriers—is emphasised in the guidance. The key priority is to understand the mechanisms causing long covid, so that organ complications might be managed early to prevent long term symptoms and serious adverse consequences and to enable individuals to return to their normal lives as soon as possible.

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