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Long COVID guidelines need to reflect lived experience

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Since May, 2020,[1] increasing attention has been given to the experiences of people with COVID-19 whose symptoms persist for 4 or more weeks. According to the Office for National Statistics (ONS), an estimated 186 000 people (95% CI 153 000–221 000) in private households in England currently have COVID-19 symptoms 5–12 weeks or longer after acute infection.[2] The ONS estimate that one in five people have symptoms that persist after 5 weeks, and one in ten have symptoms for 12 weeks or longer after acute COVID-19 infection.[2] Research on long COVID is growing, including into the underlying pathology, consequences, and sequelae, as well as rehabilitation for patients. Evidence suggests that a considerable proportion of people with long COVID have severe complications.[3–5]

We have lived experiences of long COVID, with a range of symptoms lasting for more than 6 months. Staff in the UK National Health Service (NHS) have been variously supportive or disbelieving of our ongoing, often worsening, symptoms. Before our illness we were fit, healthy, and working in demanding roles, including as doctors, nurses, and other health professionals. Our symptoms of acute COVID-19 included dyspnoea, dry cough, fever, anosmia, and debilitating fatigue. Throughout 2020 we also experienced other symptoms and conditions, never experienced before our acute illnesses (panel). All of these conditions began during, or shortly after, acute COVID-19. We each are experiencing different patterns and varied severity of symptoms; we all share difficulties accessing adequate health-care services; some of us have received misguided assessment and treatment in some of the UK's recently established long COVID clinics and encountered dismissive behaviour from some health professionals.[6–8] We share these experiences with thousands of people we engage with in rapidly growing online support groups.

We were encouraged by the announcement, on Oct 5, 2020, that the National Institute for Health and Care Excellence (NICE), the Scottish Intercollegiate Guidelines Network (SIGN), and the Royal College of General Practitioners (RCGP) were developing "a guideline on persistent effects of COVID-19 (long COVID) on patients",[9] consulting with a broad range of professional groups and some people with long COVID.

The final NICE–SIGN–RCGP guideline, published on Dec 18, 2020,[10] should provide clear information on what is and is not known about the natural history of long COVID, provide guidance for health-care workers to identify cases, and inform clinical practice for the correct management of people with symptoms. Accurate assessment, diagnosis, treatment, and rehabilitation are especially important given the increasing evidence of organ pathology

***Panel:* Conditions experienced by members of the UK doctors #longcovid group**

- Myocarditis or pericarditis
- Microvascular angina
- Cardiac arrhythmias, including atrial flutter and atrial fibrillation
- Dysautonomia, including postural orthostatic tachycardia syndrome
- Mast cell activation syndrome
- Interstitial lung disease
- Thromboembolic disease (pulmonary emboli or cerebral venous thrombosis)
- Myelopathy, neuropathy, and neurocognitive disorders
- Renal impairment
- New-onset diabetes and thyroiditis
- Hepatitis and abnormal liver enzymes
- New-onset allergies and anaphylaxis
- Dysphonia

and impairment,[11] with preliminary findings from 201 patients in a prospective, longitudinal, observational study suggesting up to 66% of people with long COVID have organ damage and 25% have damage to multiple organs.[12] In our view, the NICE guideline[10] does not do this sufficiently. We are disappointed that the guideline does not adequately address the following issues.

First, the guideline needs to provide a more comprehensive description of the clinical features and physical nature of long COVID. Although we recognise that this is a "living guideline" that will evolve with increasing information on the condition, the clinical case definition of long COVID in the guideline does not adequately describe the varied symptoms experienced beyond the limited number of symptoms and signs listed in an annex towards the end of the guideline. Although the guideline notes that symptoms may fluctuate and often present as overlapping clusters, there is insufficient consideration of the apparent relapsing–remitting nature of the condition, which risks patients being discharged from clinics during a time of remittance of symptoms but before resolution of the condition. Although we value the holistic and multidisciplinary approach of the guideline, a greater emphasis on the broad range of symptoms would assist clinicians in the assessment, diagnosis, and treatment of physical complaints associated with long COVID,[3,13,14] and the need for ongoing monitoring and repeated investigations of symptoms. The guideline is overly focused on self-management, psychological support, and rehabilitation, resulting in the potential for "watered-down" versions of NHS long COVID clinics that do not provide thorough physical assessment of patients.

Second, the guideline does not sufficiently describe what is known about the underlying pathology and the natural history of long COVID. There is no mention of the three theories of persistent virus in immune-privileged sites, aberrant immune response, or autoimmunity.[15] In the guideline there are implicit assumptions about the nature of long COVID, which could result in some likening it to post-viral fatigue and may lead to providers over-emphasising a psychological component. At the very early stage of any new disease, it is unwise to presume parallels with other conditions. This approach risks mismanagement and missed pathology. Research into the natural history of long COVID is in its infancy, yet the guideline does not satisfactorily address what is known about the complexities of the disease course, including development of new symptoms and severe abnormalities months after the acute phase of COVID-19.[16] Instead, the guideline introduces new definitions and nomenclature for different phases of COVID-19 without any clear rationale, defining acute COVID-19 (signs and symptoms of COVID-19 for up to 4 weeks), ongoing symptomatic COVID-19 infection (signs and symptoms of COVID-19 from 4 to 12 weeks), and post-COVID-19 syndrome (signs and symptoms that develop during or after an infection consistent with COVID-19, continue for more than 12 weeks, and are not explained by an alternative diagnosis). This seemingly arbitrary construct implies a linear course and risks damaging patient care by creating barriers to services and investigations.

Third, in developing the guideline we believe a more thorough participative and open process was needed to consider and determine appropriate terminology by involving a broad range of experts, including people with lived experience.

Although the guideline acknowledges that "the term 'long COVID' is commonly used", the use of new nomenclature in the NICE guideline, notably the use of the term post-COVID-19 syndrome, is in our view rooted in unfounded assumptions about the pathology and not grounded in evidence. When explaining the rationale for terms used in the guideline, no evidence is provided beyond vague assertions—eg, "most people's symptoms will resolve before 12 weeks"—and it does not engage with the fact that the term "post-COVID" does not accord with what is understood about the natural history of long COVID. Despite the explanation given for the choice of "post-COVID-19 syndrome", some will interpret this new terminology as suggestive of some degree of recovery, and this is not borne out by what is currently known about the natural history of long COVID. We believe the guideline should have paused on introducing new nomenclature until WHO convenes an inclusive consultation process to ensure that terminology for illness beyond the 4-week acute period is scientifically, culturally, and politically accurate, and facilitates access to care for people with long-term symptoms. WHO is expected to update its guidance on the clinical

management of COVID-19 to include long COVID, and this will be a timely opportunity to secure global agreement on the correct approach to clinical case definition and terminology.[17]

We look forward to this "living guideline" taking into account future WHO guidance, including on clinical case definition and terminology, and fully incorporating the perspectives and expertise of the hundreds of thousands of people who are living with long COVID, many of whom have substantial clinical experience alongside lived experience. Only then can health-care providers deliver the best possible care, assessment, diagnosis, and treatment in partnership with the growing population of people living with long COVID.

To tackle this new and complex condition optimally, we propose that all clinics caring for people with persisting symptoms after acute COVID-19 provide a thorough physical assessment by a consultant physician from a medical specialty, addressing first and foremost identification and management of any organ or multisystem dysfunction. Psychological aspects of disease should be managed as part of the recovery process, but not seen as the primary treatment focus for all. Individualised rehabilitation plans are crucial—not a one-model-fits-all approach. Long COVID health-care services are also needed for children and young people. There should be greater inclusion of people with long COVID in clinical trials for potential COVID-19 treatments, including early interventions in the acute phase to prevent long-term complications, and there is a need for more long-term cohort studies of long COVID. Additionally, a nationwide register should be established of people with long COVID, and governments should report the data from this register with COVID-19 outcome data.

Guidelines must represent the complexity of long COVID, including the areas where evidence is still emerging. Hasty attempts to rename the condition or compare it to other conditions is a disservice to thousands of people, and could result in missed pathology to the detriment of the patient. Comprehensive long COVID guidelines are essential to prevent an epidemic of long-term, chronic disease as a result of early mismanagement of pathology, and the potential implications of such an epidemic for health systems and economies.

RG is a member of the NHS Long Covid Taskforce, the Long Covid Support Group, and a Global Fund TRP Focal Point. NM receives funding from the National Institute for Health Research and is a member of the UK doctors #longcovid group. CR is a member of UK doctors #longcovid group, Long Covid Support Group, and the NHS Long Covid Taskforce. MO'H, SE, LA, NR, and CH are members of the Long Covid Support Group and the NHS Long Covid Taskforce; all were part of a stakeholder group that commented on the NICE long COVID draft guidance, as did RG, NM, and CR. WN is Honorary Assistant Professor at the London School of Hygiene & Tropical Medicine and a co-founder of PRePster, a not-for-profit advocacy group for PrEP access.

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