MANAGEMENT OF LONG COVID

From doctors as patients: a manifesto for tackling persisting symptoms of covid-19

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We write as a group of doctors affected by persisting symptoms of suspected or confirmed covid-19. We aim to share our insights from both personal experience of the illness and our perspective as physicians.

Tackling this problem will involve collaboration between politicians, healthcare services, public health professionals, scientists, and society. We call for the following principles to be used so that the best possible outcomes can be achieved for all people affected by persisting symptoms of covid-19.

- **Research and surveillance**—persisting symptoms of covid-19 should be dealt with using a scientific methodology and without bias. People experiencing them should be counted.

The effects of the virus should be studied in the way that any other disease would be, with thorough attention paid to epidemiology, pathophysiology, and management. “We still know very little about covid-19, but we do know that we cannot fight what we do not measure.” 39 Research and surveillance need to capture the full spectrum of disease, including in those not admitted to hospital and not tested, to build an accurate picture of covid-19 phenotypes. We need a clear definition for recovery from covid-19. While further evidence is awaited, clinicians should “be open about uncertainty and transparent in the ways in which we acknowledge the limitations of the imperfect data we have no choice but to use.” 40 We argue that this means accepting an emerging picture that prolonged symptoms are having a substantial impact on a significant minority of people and acknowledging that death is not the only outcome to measure. We argue that further research into chronic covid-19 symptoms is essential. Failure to understand the underlying biological mechanisms causing these persisting symptoms risks missing opportunities to identify risk factors, prevent chronicity, and find treatment approaches for people affected now and in the future.

- **Clinical services**—services need to be timely, tailored to individuals’ presentations, and involve investigating and treating pathology, as well as the functional recovery of individuals.

Many patients who may, under normal circumstances, have been admitted to hospital instead managed their extremely difficult symptoms at home during this crisis. We should not assume that pathology is different between patients who were admitted to hospital and those who were not. Before any active rehabilitation can start, organic pathology needs to be detected and managed with appropriate investigations. A rehabilitation prescription can then be made for the individual. As Lynne Turner-Stokes, consultant in rehabilitation medicine, warned in a recent Royal Society of Medicine webinar, 41 “Before we get people exercising, it’s important to be sure that it’s going to be safe. We need proper evaluation of cardiac and respiratory function, and we need to take things slowly and in a paced measure.” A recent study in *JAMA* of 100 patients (67 of whom had not been admitted to hospital) undergoing cardiac MRI after covid-19 found “cardiac involvement in 78 patients (78%) and ongoing myocardial inflammation in 60 patients (60%).” The authors say that participants “with mostly home based recovery had frequent cardiac inflammatory involvement, which was similar to the hospitalised subgroup with regards to severity and extent.”

The establishment of one-stop clinics will allow pattern recognition and expertise to develop among clinicians identifying and managing sequelae of covid-19. These clinics should reflect the multisystem nature of covid-19 and involve multidisciplinary teams with access to relevant investigations to detect known complications of covid-19 as indicated after clinical review. A reliance on “one size fits all” online rehabilitation services risks serious harm to patients if pathology goes undetected and is a missed opportunity for clinicians to develop their experience with the sequelae of this virus that is set to be an ongoing presence in our clinical practice. Where current guidance has been issued, such as the statement from the National Institute for Health and Care Excellence cautioning against graded exercise therapy in the context of covid-19, it should be communicated quickly to clinicians on the front line.
● Patient involvement—patients must be involved in the commissioning of clinical services and the design of research studies.

“No decision without me” lessons learnt from other illnesses have shown the importance of involving those most affected. Patients experiencing persisting symptoms of covid-19 have a great deal to contribute to the search for solutions. Involving patients in research design and the commissioning of clinical services will ensure that the patient perspective is listened to and will optimise the development of such studies and clinical services. This may take the form of representatives from patient formed groups, which may include signatories of this letter, liaising with policy makers, researchers, and healthcare leaders.

● Access to services—clinical services commissioned should not unfairly discriminate against those with negative tests and a clinical diagnosis should be adequate for accessing any appropriate services.

Widespread testing was not available in the early days of the pandemic. The timing of tests for active covid-19 infection (such as RT-PCR tests) affects test performance, and even if performed at an optimal time, the test is associated with a considerable risk of false negatives. We know antibody tests have mainly been validated in patients in hospital and are poorly sensitive early in the illness. There are few data regarding testing later in the disease course, and false negatives seem to be common. Some people do not seroconvert despite having previously tested positive. Thus, adherence to positive test results as a criterion for access to medical services or specific covid-19 sick pay arrangements with employers is unacceptable in the context of a clinical diagnosis of covid-19.

We welcome increasing awareness of the problem of persisting symptoms of COVID-19. As politicians, scientists, and doctors attempt to tackle this issue, these principles can act as a guide enabling the experiences of those with the condition to inform the efforts of experts and lead to improved research and clinical care, benefiting those affected and society as a whole.

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Competing interests: DC reports personal fees from Emergent BioSolutions, outside the submitted work. NH reports grants from National Institute for Health Research UK and grants from the Welcome Trust, outside the submitted work. MT is cancer clinical lead of South West London CCG (Merton).

5 Torjesen I. NICE advises against using graded exercise therapy for patients recovering from covid-19. BMJ 2020;370:m2912. doi: 10.1136/bmj.m2912 pmid: 32694164
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