

## The risk of long covid must be a primary consideration in policy decisions

January 12, 2021

Dear prime minister,

In your address to the nation on 4th January 2021 you said the following regarding the vaccination programme: "By the middle of February ... we expect to have offered the first vaccine dose to everyone in the four top priority groups identified by the joint committee on vaccination and immunisation....If we succeed in vaccinating all those groups we will have removed huge numbers of people from the path of the virus. That will eventually enable us to lift many of the restrictions we have endured for so long"

We have no doubt that the population is desperate to return to previous freedoms, to be able to return to work, socialise and spend time in close proximity to friends and family members. However, we and many of those still suffering from long covid after managing acute covid-19 in the community in the early months of 2020 are extremely concerned at the potential consequences of such a decision.

There will inevitably be a delay between the vaccination of the most "at risk" groups and the rest of the population. Hospital admissions and deaths will no doubt decrease significantly, the news media will move on to other issues and the country will heave a communal sigh of relief. However, if all or most restrictions are eliminated during this period, we run the risk of the virus circulating freely among younger people. [1] We will then likely see a huge rise in the number of those going on to develop long covid.

We learn from provisional figures released by the ONS that 10% of those infected with covid-19 go on to suffer symptoms for over 12 weeks. [2] As yet we do not have data for longer time periods, but recent research suggests that many continue to suffer for seven months or more and evidence from patient groups supports this. It is not yet established whether or not these long-term symptoms may lead to chronic disease and permanent disability. [3]

Unfortunately, we still don't know exactly who is at risk from long covid and so cannot vaccinate this group prospectively. This cohort will be working age people who are contributors to the economy and who will develop a debilitating condition for which there is currently no effective treatment. Their transformation from taxpayers to consumers of NHS resources will be keenly felt. There are already very concerning numbers of previously healthy people with long covid who require sick pay and disability benefits. More are joining them in this wave of the pandemic and a further catastrophic increase must be avoided at all costs.

We appreciate that decisions on relaxing restrictions are not easy ones for any government to make. However, we urge you not to base these decisions on deaths and hospital admissions alone. It would be very short-sighted indeed to ignore the potential for a huge increase in people with long-term ill-health on top of those already suffering.

We are asking you to please make long covid a primary consideration in your policy decision making for lifting restrictions. The potential for covid-19 to cause significant morbidity is now recognised, and both NICE and NHS England are making provision for assessing, diagnosing, and treating those affected. The availability of a vaccine does not mean that we can relax containment measures – we must continue to test, trace and isolate sufferers, take steps to make schools safe and most importantly ensure that the public is apprised of their ongoing risk so that as individuals they continue to be mindful of the consequences of infection.

on behalf of **LongCovidSOS**,

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**Leanne Ford** is a patient advocate.

**Tom Stayte** is a patient advocate.

**Competing interests:** We are members of the NHSE Long Covid Taskforce, and as members of LCSOS were stakeholders in the development of the NICE guidelines on Long Covid.

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