

Long Covid Briefing

Prepared for the Health, Social Care and Sport Committee, Welsh Parliament

Introduction

The National Institute for Health Research (NIHR) Centre for Engagement and Dissemination (NIHR CED) aims to engage people in knowledge exchange to develop and improve health and social care. One of the ways we do this is through our Themed Reviews. These are not systematic reviews of all the evidence. Nor are they guidance or recommendations for practice. Instead they are narratives based on a selection of different kinds of evidence chosen to illuminate and inform discussions focused on actions for practice. They are guided by a diverse Steering Group, including experts by experience. As far as possible, they highlight UK evidence that takes into account the UK infrastructure and culture, often funded by the National Institute for Health Research. Themed reviews include both academic study and practical wisdom from lived experience.

Our reviews of Long Covid

In October 2020, we published our first review on enduring symptoms [called “Living with Covid 19”](#). We worked closely with a group of people with lived experience and with healthcare professionals to make sense of the limited evidence. Whilst there remain significant uncertainties, more evidence has emerged since October and our second review will be published in March 2021, including the results of our survey of 3,268 people with Long Covid.

Incidence and Prevalence of Long Covid

Despite case definitions being produced by NICE and by the WHO International Statistical Classification of Diseases and Related Health problems. (ICD), research studies use different inclusion and exclusion criteria resulting in a wide range of estimates. Some studies have a limited list of symptoms for inclusion but Davis et al (2020) patient led survey identified 205 different symptoms related to 10 different systems. Some studies require a positive confirmation of a Covid19 infection but community antigen testing (polymerase chain reaction [PCR] swabs) was suspended in the UK in March 2020 and 82% of respondents to our survey said community testing was not available at the time of their initial infection. This lack of testing was also noted by Varsavsky et al. (2021), who reported that only 40% of those who reported classic symptoms on the Zoe Covid Symptom Study App had gone on to receive a test. Some people also test negative and in our survey, 46% who were tested (antigen or antibody) received a negative results despite have symptoms consistent with the virus. This means that current estimates are provisional and may go up.

The largest sample to date is from ONS in their random, representative sample of the community population through the Coronavirus Infection Survey (CIS). Everyone in the sample is swabbed at every follow-up visit, irrespective of symptoms or recent contacts, and thus there is no dependence on the broader community testing paradigm of the day. They stress that results are provisional and may be revised. Currently they estimate that 20% of all people who had tested positive for Covid19 exhibit symptoms for 5 weeks or longer and 10% exhibit symptoms for a period of 12 weeks or longer. ONS added a new question to the CIS survey in February 2021 allowing respondents to state the impact long COVID has had on their day-to-day activities, and including an expanded list of symptoms. Recognising

that some people with symptoms may test negative this question will not be dependent on a positive test finding and therefore may increase the estimated percentages.

At present the best we can say is that **at least 10%** have continuing symptoms associated with Covid19 for 12 weeks. We are less certain about how a) debilitating their symptoms are and b) how many people have enduring symptoms at nine months and one year.

Long Covid is more frequent reported by women and by younger people (including children), in a reversal of the incidence rates for hospitalisation and mortality in acute Covid19. There is little data about ethnicity and the rate of Long Covid in these groups is unclear. Seldom heard voices including traveller populations, prison populations, people with learning difficulties and frail older people are not visible in the prevalence studies.

One syndrome or many?

The NICE case definition is based on duration of symptoms and not on the nature of the symptoms. Most studies report the incidence of a single symptom (not the same symptom for all respondents) at a given point in time. There is increasing evidence of different patterns of symptoms and evidence of different pathogenesis that has led some to hypothesise that there are different mechanisms at play. Different sub groupings of Long Covid that may require different investigations and different treatment plans.

Stability of condition

There is evidence that some people are at risk of deterioration in their health, weeks after the initial infection appears to have resolved. Ayoubkhani et al. (2021) reported a study comparing 47,780 individuals discharged from hospital after a Covid19 infection with controls matched for demographic and clinical characteristics. People discharged from hospital following a Covid19 infection were 3.5 times more likely to be readmitted and 7.7 time more likely to die within 140 days than controls. The risks of readmission was greater for people under 70 than over 70 years, and for ethnic minority groups than the white population. Mandal et al (2020) reported that 9% of patients in a Long Covid clinic had X rays showing deterioration seven to eight weeks after discharge from hospital. Abnormal biomarkers are seen in substantial numbers of people after discharge, notably elevated D –dimer levels (a test used to help diagnose clotting) and raised levels of C-reactive protein (CRP, which measures inflammation) up to three months after discharge (Mandal et al. 2020 ;Venturelli et al. 2021)

Less is known about deterioration in people who were not admitted to hospital although emerging findings are suggesting clinical deterioration for this group as well. Prospective scans have demonstrated ongoing impairment in one or more organs in people not admitted to hospital. (Dennis et al 2020).

Psychological impact

Tomasoni et al. (2020) found 30% of people had anxiety and/or depression between one and three months after clearance of the Covid19 virus and this was not statistically related to gender or age. This does not mean that there is no underlying and/or overlapping physical mechanisms. We know from other long term physical conditions (such as heart failure and lung disease) that adjusting to changed health status can lead to depression and anxiety and the National Collaborating Centre for Mental Health

(2018) asserted that two thirds of people with a long term condition will also have a mental health problem, mostly depression and anxiety disorders.

One of the most frequently reported symptoms is cognitive dysfunction, or ‘brain fog’. Hampshire et al. (2020) found people who had recovered from Covid19 exhibited significantly more cognitive deficits when compared against controls.

What other impact does Long Covid have?

One area of note is the impact on employment. In our survey, 67% of respondents were aged between 25 and 55 and 81% had been in paid employment at the time they became ill and 80% said it had affected their ability to work with 36% saying their symptoms were affecting their financial status. Similar findings are reported by Davis et al. (2020) and Halpin et al. (2021). 71% in our survey said Long Covid was affecting family life and relationships with 39% saying it was impacting their ability to care for their children or other dependents.

Some people are so debilitated that they cannot manage their personal care. Vaes et al. (2020) and Venturelli et al. (2021) reported that both report large increases in people are no longer independent after a Covid19 infection.

Recommendations

Long Covid can be a multi-system disease in some and a number of researchers have identified discrete patterns of symptoms. The emergent nature of the understanding of Long Covid emphasises the need to continue to explore a range of hypotheses. We recommend that people living with Long Covid (who are experts by experience) should be equal partners in setting the research agenda.

Better understanding of the nature of Long Covid, and any sub divisions, is needed before the scale of the problem can be fully understood. We recommend that a minimum data set for recording a wide range of symptoms be agreed and used by both researchers and healthcare providers.

Long Covid is a significant health burden that is unlikely to be met by existing NHS services and new delivery models that allow rapid access are needed. We recommend rapid evaluation of different service models and skill mix for supporting people with Long Covid.

Some elements of Long Covid are similar to other conditions and interventions (pharmaceutical, psychological and physical therapies) may improve symptoms. We recommend evaluation of the use of interventions that have been effective in other conditions when used with people with Long Covid. For non-pharmaceutical interventions, a range of research methodologies should be encouraged.

Seldom heard voices are not visible in the current evidence. We recommend research that is targeted at vulnerable people (including older people and people with Learning Disabilities) as well as hard to reach groups including travellers and prison populations.

Dr Elaine Maxwell
Content Lead, NIHR CED

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