

Health Scrutiny 2022 Long Covid

Report from University Hospitals of Leicester NHS Trust

Update on PHOSP-COVID study and COVID recovery programme

1) PHOSP-COVID study

PHOSP-COVID is a multi-centre, UK-wide, observational study of patients discharged from hospital following a clinical diagnosis of COVID-19. It has been awarded £8.4million jointly by UK Research and Innovation (UKRI) and the National Institute for Health Research (NIHR). Led by the National Institute for Health Research (NIHR) Leicester Biomedical Research Centre, the PHOSP-COVID study draws on expertise from a consortium of leading researchers and clinicians from across the UK to assess the impact of COVID-19 on patient health and their recovery. It involves 53 institutions and 83 hospitals. Over 7000 participants have been recruited with 2750 volunteering to attend clinical research visits.

We published our results at one-year after discharge as a 'pre-print' (not peer reviewed) 15th Dec, 2021 and is under review currently with Lancet Respiratory Medicine. We presented to national and international media via the Science Media Centre and the story was picked up by TV, radio and newspapers.

2,230 adults who had been discharged from hospital with COVID-19 completed a five-month assessment; and 807 people completed both a five-month and one-year assessment. Recovery was measured using patient-reported data, physical performance and organ function tests. Participant blood samples at the five-month visit were analysed for nearly 300 proteins linked to inflammation and immunity.

From five months after discharge there was limited recovery at one-year. Specifically, less than 3 in 10 patients reported they felt fully recovered at one year, largely unchanged from 2.5 in 10 at five months. The most common ongoing symptoms (Long COVID) were fatigue, muscle pain, physically slowing down, poor sleep and breathlessness. Participants felt their health-related quality of life remained substantially worse one year after hospital discharge, compared to pre-COVID. People who were less likely to make a full recovery from COVID-19 were female, obese, and required invasive mechanical ventilation (IMV) to support their breathing during their hospital stay.

A cluster analysis, which is a mathematical method to group participants according to similar traits, identified four distinct groups based on the severity of physical, mental and cognitive (akin to 'brain fog') impairments experienced at five months. The number of persistent symptoms was much higher in the 'very severe' group compared to the 'mild' group. In all clusters, there was little improvement in physical and mental health from the five-month to one-year assessments. Obesity, inflammation and low walking performance were associated with the very severe impairments and highlight potential treatment targets in relevant patients.

We compared the blood profiles across the four clusters and identified higher levels of proteins, associated with whole-body inflammation and tissue damage and repair, in participants with very-severe Long COVID compared to mild. We also found other proteins were higher in those in the cluster of patients reporting symptoms such as 'brain fog' or slowed thinking, suggesting possible

neuro (brain)-inflammation. This data helps understand the potential underlying causes of some of the ongoing problems for people with Long COVID.

Over half a million people in the UK have been admitted to hospital as a result of COVID-19, so a sizeable population are at risk of persistent ill-health and reduced quality of life. Our results highlight the need for holistic and proactive care after patients leave hospital and support the approach used by the UHL NHS Trust Long COVID service for LLR. Our data suggests a personalised medicine approach to the treatment of Long Covid is needed where different patients are likely to benefit from specific treatments rather than a 'one size fits all' approach. We are currently conducting a clinical trial of different rehabilitation strategies, and are planning intervention trials with anti-inflammatory medication and medication for weight management.

2) Covid Recovery Programmes

Your COVID Recovery® is a 'light touch' digital recovery programme for individuals recovering from long COVID. The site was developed by a core team at the University Hospitals of Leicester NHS Trust with support of national experts in symptom management and representation from a wide range of health professional societies. Financial support was provided by NHS-E and an educational grant from an international pharmaceutical company.

The programme is highlighted in the UK Government recovery plan from long COVID (NHS England and Improvement, 2021) and was highlighted in the NICE guidance on long COVID (National Institute for Health and Care Excellence, 2020). The site has two components: phase one and two. Phase one is an open access site (www.yourcovidrecovery.nhs.uk) and is available worldwide and provides advice on managing common symptoms. Phase two is a password protected site that patients can access following an assessment by a healthcare professional (HCP).

Site navigation and content was developed in collaboration with individuals who have experienced Long COVID. The precise content of the site was developed by individual HCPs, specialists in their field and specialists representing major professional bodies in the UK. All content was peer reviewed by additional experts, patients and the communications team at NHS England for readability. Embedded into the site are two outcome measures: the EQ-5D and the COPD assessment test .

Phase 1 data (06/01/2022)

- Current website views:
 - o P1 visitors: 5.10 million
 - o P1 page views: 9.70 million
- This week 502,069 users have accessed the YCR website, with 694,266 page views.
- Top pages include the taste and smell, cough, chest pain, musculoskeletal shoulder and back pain and dizziness.

Phase 2 is a password protected supported self-management programme, supported by a team at UHL. UHL is responsible for training and 'on boarding' all interested sites. To date we have trained in excess of 120 sites across England.

Phase 2 data

- Number of sites: 137
- Number of patients: 1,695

Early data from those who have graduated from the programme indicate improvements in these 2 outcomes. This data has no control group and we have recently received funding to conduct a small randomised controlled trial. (There was an increase in EQ VAS score (pre =48.84 [19.51]; post = 59.87 [22.14]; $p < 0.001$), with a mean difference of 11.03. There was also an increase in EQ-5D Index Value pre- to post-intervention (pre =0.52 [0.25]; post = 0.57 [0.27]; $p = 0.089$), with a mean difference of 0.05.)

1. Face to face rehabilitation

In response to the increasing burden of long Covid, a Covid specific rehabilitation programme was offered, that utilised clinical sessions that would under normal circumstances be pulmonary and cardiac rehabilitation programmes.

The rehabilitation programme was 6 weeks in duration, with two supervised sessions per week. The programme comprised of aerobic exercise (walking/treadmill based), strength training of upper and lower limbs and educational discussions with handouts from the www.yourcovidrecovery.nhs.uk website. The education sessions included: breathlessness, cough, fatigue, fear and anxiety, memory and concentration, taste and smell, eating well, getting moving again, sleeping well, managing daily activities and, returning to work.

The programme has limited capacity currently (as we are now delivering pulmonary and cardiac rehabilitation) but we have recently received funding to expand capacity in collaboration with LPT (posts currently out to advert).

Early data published (Daynes E et al CRD 2021) identified important improvements in functional capacity, health related quality of life, breathlessness, fatigue and cognition. We will be offering the programme across Leicester and Leicestershire.