

Wales COVID-19 Evidence Centre (WCEC)

Summary of Active and Prospective Long-COVID Research in Wales Report 000017 – November 2021

Report Details

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1. Background

This summary of research studies into Long COVID aims to describe the current and prospective work that is happening in Wales. It also aims to highlight opportunities for participation in this research, both for people with Long COVID, and health care professionals involved in their care.

'Long COVID' is a term that is being widely used to describe the symptoms that continue or develop weeks or months following acute COVID-19 infection. It includes both 'ongoing symptomatic COVID-19' (from 4 to 12 weeks) and 'post-COVID-19 syndrome' (12 weeks or more). Symptoms include persistent shortness of breath, tiredness, muscle aches and mood disturbance, and can be significant and debilitating for patients.

Data from the [ONS](#) show that as of 2 October, an estimated 1.2 million people (1.7% of the UK population) self-reported symptoms persisting for more than 4 weeks after first suspected COVID-19 infection. Of these, two thirds reported that the symptoms adversely affected their day-to-day activities.

An [NIHR review](#) into Long COVID in March 2020 concluded that the condition remains poorly understood and there is a significant need for further research. Long COVID is a broad term and there is no consensus on clinical definition; researchers have suggested different classifications based on duration and symptoms, raising further questions about how this might affect management. The causes are thought to be multifactorial and are unclear; there is no definitive diagnostic test and no proven treatments.

Long COVID is likely to cause both individual and societal economic harms due to inability to work and loss of productivity. In addition, Long COVID can be a multi-system condition and patients need appropriate investigation and clinical interventions.

2. Long COVID research

Further research is required to shape local services to meet these needs. Better understanding of the causes and incidence of Long COVID will enable prediction of where services are needed and how to prevent complications. Evaluation of interventions for symptom improvement and service models to deliver these interventions will also aid future service planning.

The UK [NIHR commissioned 15 studies](#) into Long Covid (starting June 2021 onwards). This builds on an earlier programme commissioned by [UK research and innovation](#) in 2020.

People with Long COVID who live in Wales may wish to participate in this valuable research. The following Long COVID research studies are currently active or planned in Wales. Here we provide a summary of each and where further information about participation can be found. This may be via individual enquiries to the study team, or participation may sometimes only be possible via a clinic.

Further **information and support for prospective participants, professionals and researchers** can be found via the Health and Care Research Wales [Support and Delivery Service](#). (Email: research-supportmystudy@wales.nhs.uk).

3. Long COVID research studies currently active in Wales

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| <u>PHOSP-COVID</u> | <p>Post-hospitalisation COVID-19 study: a national consortium to understand and improve long-term health outcomes (PHOSP-COVID)</p> <p>https://www.phosp.org/</p> |
| What is this study about? | <p>UK wide study aiming to understand the long-term effects on patients who have been hospitalised with COVID-19 and the ongoing medical, psychological and rehabilitation needs of those patients.</p> |
| Can I take part? | <p>This is an epidemiological study, therefore there are no treatments involved. Information is collected from the participants' medical records and some participants may be asked for additional samples and tests.</p> <p>Participants are invited to take part via letter. Patients who have previously been hospitalised with COVID-19 and who wish to take part in the study may also check eligibility and sign up themselves via the <u>PHOSP-COVID website</u>.</p> |
| <u>HEAL-COVID</u> | <p>HElping Alleviate the Longer-term consequences of COVID-19 (HEAL-COVID): a national platform trial</p> <p>https://www.heal-covid.net/</p> |
| What is this study about? | <p>UK wide clinical trial aiming to identify treatments that may be beneficial for people discharged from hospital after recovering from COVID-19.</p> |
| Can I take part? | <p>This is a clinical trial involving different treatments. Please see the <u>study website</u> for more information.</p> <p>Participants cannot sign up themselves. Patients admitted to hospital with COVID-19 will be eligible for the study and recruited in hospital prior to discharge. Currently there are eight hospitals in Wales set up to recruit participants (Bronglais General Hospital, The Grange University Hospital, Morriston Hospital, Princess of Wales Hospital, Singleton Hospital, University Hospital of Wales, Ysbyty Glan Clwyd and Ysbyty Gwynedd).</p> |
| <u>REGAIN</u> | <p>Rehabilitation Exercise and psycholoGical support After covid-19 InfectioN (REGAIN): a multi-centre randomised controlled trial</p> <p>https://warwick.ac.uk/fac/sci/med/research/ctu/trials/regain/</p> |

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| What is this study about? | This study is looking to evaluate potential treatments for Long COVID . This is a clinical trial evaluating an intensive, on-line, supervised, group, home-based rehabilitation programme to support long-term physical and mental health recovery (REGAIN) vs. best-practice usual care in patients discharged from hospital after COVID-19 infection. |
| Can I take part? | <p>The study is recruiting until 31 December 2021. Participants can self-refer themselves to the study via the REGAIN website.</p> <p>Study participants should be over 18, suffering from substantial (as defined by the participant) COVID-19 related physical and/or mental health problems and have been discharged after a hospital admission related to COVID-19 infection over 3 months ago. Please see the website for more information.</p> |
| | <p>Understanding Experiences of Long COVID in Families</p> <p>https://www.phc.ox.ac.uk/research/health-experiences/understanding-experiences-of-Long-covid-in-families</p> |
| What is this study about? | <p>This is a qualitative study using interviews with patients to better understand people's experiences of Long COVID, how it may be changing family life and to find out why some families have different experiences to others.</p> <p>The interviews will be used to develop an online platform as part of the Healthtalk.org website. Hearing and sharing experiences will help in designing better health and social care support and services for all families affected by Long COVID.</p> |
| Can I take part? | <p>This study is recruiting until mid-2022.</p> <p>The study researchers are especially interested in talking with: teenagers (12-18 years) who have had Long COVID, parents of young children (younger than 12 years) who have had Long COVID, parents who have had Long COVID themselves, young people who have returned home because of their own or their parent's Long COVID</p> <p>Interested participants who have experience of Long COVID in families can get in touch by emailing Cervantée Wild at covidexperiences@phc.ac.uk or calling/texting 07795390269.</p> <p>More information can be found on the study website.</p> |

4. Upcoming Long COVID research studies in Wales

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| <u>LOCOMOTION</u> | <p>Long COvid Multidisciplinary Consortium: Optimising Treatments and services acrOss the NHS (LOCOMOTION)</p> <p>https://medicinehealth.leeds.ac.uk/dir-record/research-projects/1394/long-covid-multidisciplinary-consortium-optimising-treatments-and-services-across-the-nhs-locomotion</p> |
| What is this study about? | <p>This study looks to bring together Long COVID teams from different areas of UK and to develop best practice guidelines for the assessment and management of individuals with Long COVID.</p> <p>Assessment will take place in 'real-life' settings - Long COVID clinics, participants' homes (through use of Apps on self-monitoring wearable devices) and GP surgeries. Different workstreams will assess different aspects of Long COVID and will incorporate interviews conducted to evaluate the impact on people's ability to return to work; and the use of wearable technology for home monitoring of fluctuation of symptoms both physical and cognitive.</p> <p>Through comparison of findings across the consortium centres, more will be learnt about treatments offered, real-time education to other healthcare staff and patients will be provided, and a 'gold standard' will be established and shared with NHS services nationwide.</p> <p>Ultimately, this research aims to inform Long COVID policy and practice to reduce inequalities in Long COVID care across the UK.</p> |
| Can I take part? | <p>This study will gather comprehensive data from a sample of ten Long COVID NHS clinics, individuals' homes and primary care.</p> <p>All individuals with a diagnosis of Long COVID within participating centres will be eligible for the study.</p> <p>The Long COVID clinic at University Hospital of Wales, Cardiff will be participating in this study in Wales. Referrals can be made to this clinic via your GP.</p> |
| <u>LISTEN</u> | <p>Long Covid Personalised Self-managemenT support- co-design and EvaluationN (LISTEN)</p> <p>https://www.cardiff.ac.uk/centre-for-trials-research/research/studies-and-trials/view/listen</p> |
| What is this study about? | <p>This study is developing an intervention consisting of a package of self-management support, co-designed with individuals living with long COVID and other stakeholders. The aim is to compare this intervention with usual care in the NHS to explore whether it can help patients manage Long COVID symptoms in everyday life.</p> <p>In the first part of this study, participants living with Long COVID will work with researchers to design a package of self-management support personalised to their needs.</p> <p>In the second part of this study, individuals with Long COVID will be recruited to a clinical trial to evaluate the new intervention.</p> |

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| | <p>The LISTEN intervention will be evaluated in terms of impact on participation in routine activities, emotional well-being, social participation, fatigue, self-efficacy and quality of life. To understand the economic impact of the intervention, the costs will be evaluated by recording healthcare resource use, expenses and loss of working hours.</p> |
| Can I take part? | <p>The study will be recruiting from January 2022. Participants must be aged 18 or over and experience persistent illness following COVID-19 infection for over 12 weeks. They must not have been hospitalised during the acute COVID-19 illness.</p> <p>Further information can be found on the study website and there is an expression of interest form for those interested in participating in the study.</p> <p>There will also be a telephone number available for participation enquiries and this will be available on the website.</p> |
| | <p>The immunologic and virologic determinants of Long-COVID</p> |
| What is this study about? | <p>This research aims to provide new insights into the cause of Long COVID and to explore whether Long COVID results from the impact of the coronavirus on the body's immune system.</p> <p>The researchers will evaluate whether the virus causes reactive autoimmune diseases (through coronavirus stimulation of the body's natural defence systems); also, they will assess if the virus persists in the body longer term triggering ongoing immune activation.</p> <p>The project hopes to identify markers to indicate which patients with COVID-19 subsequently develop Long COVID. These biomarkers will, in turn, contribute to the development of new diagnostic tests and treatments for Long COVID.</p> |
| Can I take part? | <p>Study participants should be aged 18 years or over and able to provide informed consent. All participants should have a clinical diagnosis of Long COVID made through specialist assessment in a designated Long COVID clinic/service [NICE guideline NG188]. Those receiving immunosuppressive medication or suffering from underlying immunological disease are <i>not</i> eligible to participate.</p> <p>The Long COVID clinic at University Hospital of Wales, Cardiff will be participating in this study in Wales. Referrals can be made to this clinic via your GP.</p> |
| EXPLAIN | <p>HypErpolarised Xenon magnetic resonance PuLmonary imAging in patieNts with Long COVID (EXPLAIN)</p> |
| What is this study about? | <p>This study looks to understand why some individuals with Long COVID continue to struggle with breathlessness and have a reduced ability to exercise despite usual tests, including computerized tomography (CT) scans, being normal.</p> <p>It may be that CT imaging is not sensitive enough to pick up subtle abnormalities therefore, the researchers will use state-of-the art Magnetic Resonance Imaging (MRI) scanning performed</p> |

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| | <p>whilst breathing in a harmless special gas (hyperpolarised xenon). This technique does not involve radiation exposure and enables sensitive evaluation of the lung tissue to measure ventilation and transfer of oxygen across the air sacs into the blood stream.</p> |
| Can I take part? | <p>Study participants should be aged 18 years or over and able to provide informed consent. All participants should have a clinical diagnosis of Long COVID made through specialist assessment in a designated Long COVID clinic/service. Some of the participants will have been hospitalised, others will have been managed in the community.</p> <p>If the diagnosis of Long COVID was made 12-24 months ago, a clinical diagnosis (symptom based) is sufficient, however if 3-12 months since the acute infection, microbiological evidence of COVID-19 (PCR or antibody positive) is required.</p> <p>The Long COVID clinic at University Hospital of Wales, Cardiff will be participating in this study in Wales. Referrals can be made to this clinic via your GP.</p> |
| CICERO | Cognitive Impairment in long COVID: PhEnotyping and RehabilitatiOn (CICERO) |
| What is this study about? | <p>This study will look at why patients develop long term problems with memory, attention or other cognitive function (sometimes called 'brain fog') following COVID-19 infection. Magnetic Resonance Imaging (MRI) scanning will be used to identify affected brain networks.</p> <p>The findings will be used to develop and test a new rehabilitation strategy to help people recover from the cognitive aspects of long COVID and return to normal life and working ability.</p> |
| Can I take part? | <p>There are no recruiting sites for this study in Wales.</p> <p>However, clinics in England recruiting for this study are able to receive referrals from your GP in Wales. Participants should be aged between 30 and 60 years, have evidence of prior COVID-19 infection and have cognitive impairment persisting over 3 months from the acute infection.</p> <p>Please see the study website for more information when launched soon.</p> |

5. Upcoming Long COVID research studies in Wales – set up under discussion

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| STIMULATE-ICP | Symptoms, Trajectory, Inequalities and Management: Understanding Long-COVID to Address and Transform Existing Integrated Care Pathways (STIMULATE-ICP) |
| What is this study about? | <p>This study aims to improve recovery from Long-COVID. It is a clinical trial; individuals will be given usual care or a new pathway which includes MRI scanning and enhanced rehabilitation.</p> <p>Within this study, another trial will assess drug treatments; measuring the effects of these treatments on symptoms, mental health and ability to work.</p> |
| Can I take part? | Researchers are hoping to expand the study to include Wales but currently there are no recruiting sites in Wales. |