LOCOMOTION Long-COVID Study Lay Summary:

1. Background

Long Covid (LC) affects over one million people in the UK; it has various symptoms and impacts daily life. Although there are 83 LC clinics in England, most people have not had access to them, and waiting times to be seen are long. We realise the urgency for LC patients to access prompt and appropriate care in clinics and doctors' surgeries, and manage their symptoms effectively at home.

2. Aim

Our research aims to produce a 'gold standard' for care by analysing what is happening to patients now, creating new systems of care and evaluating them to establish best practice.

3. Outline Of Research

This research has been developed with LC patients and will continue to include patients working as equal partners. Key priorities of LC patients are: correct clinical assessment; advice and treatment; and help with returning to work and other roles. This research is also based on the experience of a wide range of NHS professionals already treating people in ten LC clinics across the UK, and led by academics (universities) with links to other LC funded studies.
The research will take place in three settings: LC clinics; at home (including self-monitoring on a mobile device using a set of questions about their symptoms which are built into an application on the device); and in doctors' surgeries. We will track where patients are being referred or not referred and learn from the experience of clinics by interviewing patients and recording outcomes. Throughout the study, specialists in 'Healthcare Inequality' will reach people who are not accessing clinics for a variety of reasons. We will put in place new processes in clinics and doctors' surgeries which will be monitored throughout to ensure they are the correct standard, accessible for patients and staff, and cost-effective.

Aim: We will optimise LC management across three settings of care – LC specialist clinics (Workstream (WS)1); Homes/self-management (WS2) and Primary care (WS3).

4. Methods

This research is based around 3 Workstreams (WS)

WS1: We will standardise the options for a condition which causes multiple medical problems by using a Quality Improvement collaborative involving clinician-researchers from 10 UK-wide LC clinics. Patients and healthcare professionals will develop outcome measures and tools to inform training and resources for LC clinic assessments and treatment. Ethnic and socioeconomic inequalities of care and vocational challenges of patients will be addressed using a varienty of approaches.

WS2: A digital platform incorporating wearable technology will enable us to capture symptom fluctuations, and individual condition triggers to assist in self-management. Core outcome measures, including the Yorkshire Rehabilitation Scale (C19 YRS), will be available via the digital platform for remote monitoring and directing interventions.

WS3: Existing primary care and LC clinic integrated data will assist in developing and evaluating new integrated, cost-effective service models that will enable the best practice guidance developed in WS1 to be delivered at the point of contact in primary care. We have links with previously funded NIHR LC projects to enable co-learning and maximising impact.

More detailed descriptions of how each WS is broken down are shown in the box below:

Work Stream I (LC Clinics Quality Improvement Collaborative)

Task 1.1: Create a QI collaborative consisting of a range of LC services with geographic and organisational diversity to share knowledge, best practice and learning for best practice management of medical problems, therapy, service model and workforce.

Task 1.2: Involve individuals with LC and healthcare professionals in co-designing of equitable services and developing training packages and resources for both.

Task 1.3: Understand and address socioeconomic, gender and ethnic inequalities in LC and in LC service utilisation.

Task 1.4: Understand the vocational rehabilitation needs of a representative cohort of individuals and develop return to work programmes.

Task 1.5: Understand what types of peer support people with LC are utilising in the community and how peer support groups may be facilitated into wider LC pathways and inform the QI Collaborative of 1.1

Work Stream II (Home Monitoring and Self-Management)

Task 2.1: Using a home monitoring digital system for capturing the daily fluctuation of symptoms, recognise adverse triggers across patients from a range of demographic groups and aid self-management.

Task 2.2: Build on existing best practice for Patient Reported Outcome Measures, including validating the digital C19-YRS PROM in a diverse patient group and extend the digital system to the WHO core set of outcome measures for standardised assessment in LC.

Work Stream III (Evaluating and Developing LC Integrated Care Pathways)

Task 3.1: Harness existing (and template-augmented) integrated patient-level data across primary care and LC clinics to understand specific LC phenotypes and current care pathways and outcomes.

Task 3.2: Assess the cost-effectiveness of alternative pathways and develop and test efficient service models.

5. Outcomes

Comparing findings across our partnership of ten NHS LC Clinics across the UK, we will learn more about treatment, providing real-time education to other healthcare staff and patients, and will establish a 'gold standard' for management of LC that can be shared across the UK.