# Name of dataset

# PROMS (Patient Recorded Outcome Measures) and Demographic Data, from the NIHR-funded project, ‘Supported remote rehabilitation post Covid-19: development, deployment and evaluation of a digitally-enabled rehabilitation programme’ (Award ID: NIHR132243).

# How the data were collected / tools used

The digitally-enabled rehabilitation programme is known as LWCR (Living with Covid Recovery). It is a DHI (Digital Health Intervention) designed by a multidisciplinary team of clinicians, patient and public involvement (PPI), academics and industry partners for use as part of a care pathway in post-COVID-19 clinics. It incorporates an app for patients to use and a clinician dashboard to enable clinicians to monitor patient progress.

The DHI includes questionnaires for patient-reported outcome measures (PROMs) – see ‘What data were collected?’ for details.

The PROMs were completed by patients based on their clinical need, as determined by the patients themselves and/or their healthcare professional.

# Who were the data collected from?

Data were collected via these self-reports from 3754 Long Covid patients seeking treatment in one of 31 self-selecting specialised post-COVID-19 clinics in England and Wales that were using the app as part of their care pathway, during the study period.

# What data were collected?

## **Validated PROMs**

Validated PROMs included in the app were:

* Breathlessness
	+ **Dyspnoea-12** which gives an overall score of breathlessness impact, with higher scores corresponding to greater severity (recall period not defined, reflects current moment).
	+ **Medical Research Council (MRC) Dyspnoea Scale** which measures the degree of breathlessness related to activity, with higher scores corresponding to greater severity. The scale takes values 1–5 using the following classifications: MRC 1 (mild), MRC 2–3 (moderate) and MRC 4–5 (severe). We analysed this variable as a categorical score (recall period not defined, reflects current moment).
* Fatigue
	+ **Functional Assessment of Chronic Illness Therapy–Fatigue (FACIT-F)** which measures self-reported fatigue and its impact on daily activities and function with lower scores corresponding to greater fatigue. A threshold value of 30 was chosen in line with fatigue reported in a cancer population. Population mean value for FACIT-F in the general population has been reported as 43 (recall period: 7 days).
* Anxiety
	+ **The Generalised Anxiety Disorder Scale, Seven-Item (GAD-7)** which is used as a screening tool and severity measure for anxiety. A cut-off value of 10 or more identifies anxiety. Additionally, threshold values are also considered: no anxiety, 0–4; mild anxiety, 5–9; moderate anxiety, 10–14; and severe anxiety, 15–21 (recall period: 2 weeks).
* Cognition (brain fog)
	+ The **Perceived Deficits Questionnaire, Five-Item Version (PDQ-5)** which measures the degree to which individuals perceive themselves as experiencing cognitive difficulties. Higher scores indicate more perceived deficits. The following threshold values suggested are used: minimal, 0–8; moderate, 9–14; and severe 15–20 (recall period: 4 weeks).
* Depression
	+ The **Patient Health Questionnaire–Eight Item Depression Scale (PHQ-8)** in which score of 10 is used as a cut-off for a diagnosis of depression (recall period: 2 weeks).

## **Unvalidated questionnaires**

Unvalidated questionnaires used to collect data were:

* Working days lost
	+ A **study-specific questionnaire** to capture data on the number of working days lost in the 28 days prior to questionnaire completion. Users were asked “In the last 4 weeks how many days off work (sick leave) have you taken due to COVID-19 and/or rehabilitation.”
* Patient demographics
	+ **Patient Demographic Questionnaire:** age (year of birth), gender, ethnicity, highest level of education and patient’s postcode. This postcode provided the IMD (index of multiple deprivation).

## **Primary outcome measures**

* Functional status:
	+ **Work and Social Adjustment Scale (WSAS)** a validated questionnaire for functional impairment. Scores range between 0 and 40, with scores of 20 or more indicating moderately severe or worse impairment on daily functioning. The WSAS contains five equally weighted component scores (range 0–8) relating to impairments across the following domains:
* Ability to work.
* Home management.
* Social leisure activities.
* Private leisure activities.
* Close relationships.

Additionally, there is a further question to identify those individuals who are either retired or have chosen not to work. There is no defined recall period for the WSAS; therefore, the questionnaire reflects the current situation.

## **Secondary outcome measures**

* Quality of life
	+ **EQ-5D-5L,** a standardised measure of health-related quality of life. The EQ-5D-5L descriptive system comprises five dimensions (mobility, self-care, usual activities, pain/discomfort and anxiety/depression). For each dimension, there are five possible responses (level 1: no problems, level 2: slight problems, level 3: moderate problems, level 4: severe problems and level 5: unable to/extreme problems). The responses are coded to give a five-digit code to describe the respondent’s health state (such as 13254). Reference weights from the UK general population are applied to the resulting health states to produce a single summary index score for health status, the EQ-5D-5L index score. This is a measure anchored at 0 (representing ‘death’) and 1 (‘full health’), but it can include negative values to reflect health states judged worse than death. Similar to the WSAS, there is no recall period defined for the EQ-5D-5L; therefore, the PROM would reflect the health status on the day of questionnaire completion.

# When data were collected

The dataset includes data from patients registered on the LWCR app between 30 November 2020 and 23 March 2022. Patients were able to complete the PROMs as often as they wished.