

# Early experiences of the Your COVID Recovery<sup>®</sup> digital programme for individuals with long COVID

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## ABSTRACT

**Objectives** To describe the early data from the Your COVID Recovery<sup>®</sup> digital programme and to explore the data collected from two embedded outcome measures.

**Design** Observational.

**Setting** Primary and secondary care (England—Online).

**Participants** 110 individuals completed the programme (68.1% female, 88.1% White British, age: 46.3 (10.8) years, weight: 86.5 (21.1) kg, height: 169.3 (10.0) cm). 47.2% of patients reported comorbidities.

**Intervention** Following an assessment by a healthcare professional, individuals with long COVID were offered access to the Your COVID Recovery<sup>®</sup> digital programme. The programme comprises of four stages for the participants to progress through. Participants are encouraged to record severity of their symptoms and amount of activity they are doing on a symptom and an activity tracker. Resources and interactive material on managing symptoms of long COVID are available throughout each stage.

**Primary outcome measures** Questionnaire (EuroQoL 5-Dimension 5-Level (EQ-5D-5L) and the chronic obstructive pulmonary disease assessment test (CAT)) data were extracted from the site from 11 March 2021 until 9 November 2021.

**Results** Participants were on the programme for 8.6 (4.3) weeks. There was a statistically significant increase in EQ-5D-5L visual analogue scale (VAS) score (pre=48.8 (19.5); post=59.9 (22.1);  $p<0.01$ ). The EQ-5D-5L Index Value preintervention to postintervention did improve but not significantly (pre=0.5 (0.3); post=0.6 (0.3);  $p=0.09$ ). CAT total score improved significantly preintervention to postintervention (pre=19.8 (7.2); post=15.6 (7.6);  $p<0.01$ ). All CAT item scores significantly improved preintervention to postintervention ( $p<0.005$ ), except the phlegm item score ( $p=0.168$ ).

**Discussion** This early data describes the impact of the Your COVID Recovery<sup>®</sup> digital programme on the first cohort of patients to complete the digital recovery programme. The outcome data are promising and should encourage uptake.

## INTRODUCTION

There is a wealth of evidence that indicates there is a significant symptom burden for a high proportion of patients after an initial

## WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Objective measures in large cohorts have demonstrated that symptom burden persists in a large number of individuals post-infection with SARS-CoV-2 (COVID-19). Recommendations for rehabilitation are emerging, and little data exist on effective rehabilitation packages.

## WHAT THIS STUDY ADDS

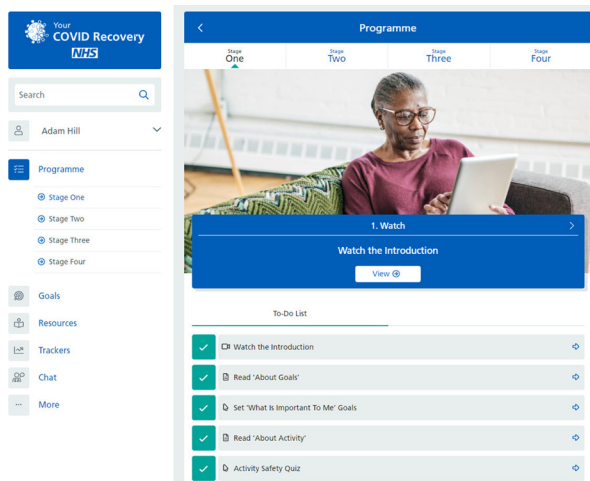
⇒ These early data describe the impact of the Your COVID Recovery<sup>®</sup> digital programme on the first cohort of patients to complete the programme.

## HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ The early data are encouraging and should be further evaluated as part of a randomised controlled trial.

acute infection with SARS-CoV-2 (COVID-19).<sup>1,2</sup> Symptoms that persist for 4–12 weeks are termed ‘long COVID.’<sup>3</sup> Recent data suggest that around 2 million people are living with long COVID in the UK.<sup>4</sup> The symptoms associated with long COVID can have a significant impact on the individual’s overall well-being.<sup>1,2</sup> Commonly reported symptoms include fatigue, breathlessness, cough, musculoskeletal pain and changes to taste and smell.<sup>3</sup> Although recommendations for rehabilitation are emerging,<sup>5</sup> models and evidence for rehabilitation are lacking. Given the likely demand for rehabilitation services and the challenges of national lockdowns, it was proposed that a digital platform may be worthy of consideration. NHS England supported the development of a site to be made freely available to long COVID services across the country.

Your COVID Recovery<sup>®</sup> is an online digital programme for individuals recovering from long COVID. The site has two components: phase one and phase two. Phase one is an



**Figure 1** A screenshot of the Your COVID Recovery<sup>®</sup> digital programme dashboard page.

open access site ([www.yourcovidrecovery.nhs.uk](http://www.yourcovidrecovery.nhs.uk)) available worldwide which provides advice on managing common symptoms. Phase two is a password-protected site, accessed following an assessment by a healthcare professional<sup>6</sup> (figure 1).

Site navigation and content was developed in collaboration with individuals who have lived experience of long COVID. The initial content of the site was proposed by individual healthcare professionals, specialists in their field and specialists representing major professional bodies in the UK who have expertise in managing many of the key symptoms associated with long COVID. All content was peer reviewed by additional subject experts, individuals with long COVID (post-admission or managed in the community) and the communications team at NHS England for readability.

The purpose of this project is to describe the early data from the Your COVID Recovery<sup>®</sup> digital programme and to explore the data collected from the two outcome measures.

## METHODS

### Participants

Following an assessment by a healthcare professional, individuals with long COVID were offered initial access to the Your COVID Recovery<sup>®</sup> digital programme. Participants could be referred from both primary and secondary care sites across England. The site was developed for individuals with persistent long COVID symptoms, displaying ongoing physical and/or psychological symptoms that were impacting their daily activities and their overall quality of life. Individuals were excluded if they demonstrated acute symptoms or required further diagnostic tests to confirm or exclude medical conditions.

### Ethical approval

These data have been collected as part of service evaluation; the purpose of service evaluation is to evaluate

the effectiveness of the Your COVID Recovery<sup>®</sup> digital programme. Moreover, the purpose of processing this information is to observe, analyse and record on a structured online rehabilitation programme for patients diagnosed with COVID or suspected COVID. Patients sign up for the use of the Your COVID Recovery<sup>®</sup> digital programme on their own volition, so the lawful basis for conducting the work of either site is consent of the patient. Healthcare providers signed a Digital Protection Agreement which states that only anonymous data will be used for the purpose of service evaluation. Data processing for any service evaluation is anonymous, meaning patients' confidential information is not shared, and patients will remain anonymous.

### Patient and public involvement

Patients were involved throughout the development of Your COVID Recovery<sup>®</sup> digital programme and in the choice of outcome measures but not specifically in the data collection.

### Intervention

Participants referred on the Your COVID Recovery<sup>®</sup> digital programme completed an initial registration stage, followed by an individualised goal setting exercise. The programme is recommended to be supported remotely by the referring healthcare professional with telephone contact advised but not mandated. The site comprises of four stages for the participants to progress through, with a list of tasks to complete each stage. Participants are encouraged to record severity of their symptoms and the amount of activity they are doing on a symptom and an activity tracker on a regular basis. The programme contains interactive and downloadable resources on managing symptoms such as cough, fatigue, fear and anxiety and topics such as eating well, getting moving again and sleeping well. The advice on symptoms is continually available, recognising the fluctuating nature of the disease trajectory.

Patients are able to contact their healthcare professional through the site for support using the 'ask your healthcare professional' email function and engage in peer-to-peer support through the site's forum. It was anticipated that individuals would take approximately 8–12 weeks to complete all four stages of the programme. The site is fully available throughout the patient journey and 12 months post-registration.

### Outcome measures

Two measures are embedded into the programme: the EQ-5D-5L<sup>7,8</sup> and the CAT.<sup>9</sup> The latter has been tested for its utility in the long COVID population and reflects the major symptoms reported.<sup>10</sup> Basic demographics (eg, age, gender and ethnicity) and questionnaire (EQ-5D-5L and the CAT) data were extracted from the site. Those with complete preintervention and postintervention

datasets were extracted from the site from the first patient completing the programme on 11 March 2021 until 9 November 2021.

### Statistical analysis

Statistical analysis was performed on SPSS V.28 (SPSS, Chicago, Illinois, USA). Preintervention and postintervention EQ-5D-5L VAS scores, EQ-5D-5L Index Values were compared using the Wilcoxon signed rank test, and the distribution of EQ-5D-5L dimension responses preintervention and postintervention was compared using a  $\chi^2$  test. Preintervention and postintervention CAT total scores were compared using paired t-tests, and the CAT item scores were compared using the Wilcoxon signed rank test. Statistical significance was set at  $p < 0.05$ . Data are presented as mean (SD) and frequency of participants as  $n$  (%).

### RESULTS

Characteristics of participants can be found in table 1. 47.2% of patients had comorbidities (respiratory 53.9%, vascular 30.8%, metabolic 50.0%, musculoskeletal 26.9%, cardiac 1.9%, gastrointestinal 26.9% and psychiatric 40.4%). The breakdown of comorbidities is reported in online supplemental appendix 1.

At baseline, the highest scored domains were lack of energy, breathlessness and activity limitation (table 2).

EQ-5D-5L VAS scores increased significantly following the Your COVID Recovery® digital programme (pre=48.8 (19.5); post=59.9 (22.1),  $p < 0.01$ ), with a mean difference of 11.0 (29.3) (95% CI 5.5 to 16.6). The EQ-5D-5L Index Value preintervention to postintervention did improve but not significantly (pre=0.5 (0.3); post=0.6 (0.3);  $p = 0.09$ ), with a mean difference of 0.1 (0.3) (95% CI -0.04 to 0.11).

The proportion of EQ-5D-5L dimension responses at baseline and at follow-up identified a significant improvement in self-care ( $p < 0.001$ ), usual activities ( $p = 0.029$ ) and

**Table 2** Mean (SD) domain responses for all patients at baseline and follow-up for COPD assessment test (CAT)

Domain	Baseline (stage 1)	Follow-up (stage 2)	P value
Cough	1.7 (1.2)	1.2 (1.2)	<0.001
Phlegm	1.1 (1.4)	1.0 (1.3)	0.168
Chest tightness	2.1 (1.5)	1.7 (1.3)	0.002
Breathlessness	3.4 (1.2)	2.4 (1.3)	<0.001
Activity limitation	3.1 (1.5)	2.4 (1.3)	<0.001
Confidence to leave home	2.2 (1.6)	1.8 (1.4)	0.001
Sleep	2.7 (1.5)	2.3 (1.5)	0.006
Energy	3.5 (1.0)	3.0 (1.1)	<0.001

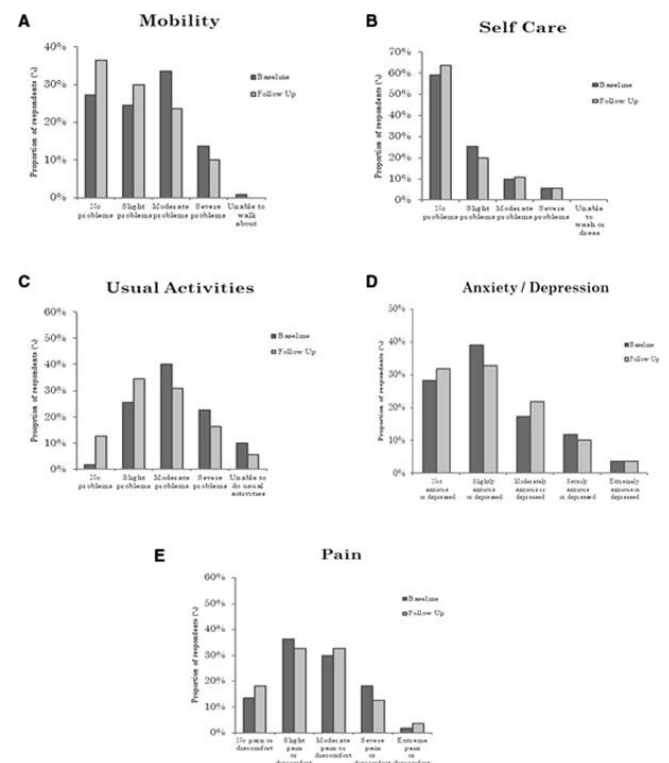
COPD, chronic obstructive pulmonary disease.

pain/discomfort ( $p < 0.001$ ) following the Your COVID Recovery® digital programme (figure 2).

The CAT total scores decreased significantly following the Your COVID Recovery® digital programme (pre=19.8 (7.2); post=15.6 (7.6),  $p < 0.01$ ) with a mean difference of 4.2 (6.4) (95% CI 3.0 to 5.4). All CAT item scores for symptom burden (breathlessness, cough, chest tightness, activity limitation, confidence to leave home, sleep and energy) improved significantly preintervention to postintervention ( $p < 0.005$ ), apart from the phlegm item score ( $p = 0.168$ ) (table 2).

**Table 1** Characteristics of 110 participants who completed the Your COVID Recovery® digital programme

Demographic characteristics	Mean (SD)
Age (years)	46.3 (10.8)
Weight (kg)	86.5 (21.1)
Height (cm)	169.9 (10.0)
Time on programme (weeks)	8.6 (4.3)
	<b>Frequency of participants, n (%)</b>
Gender (female)	75 (68.1)
Ethnicity (White British)	97 (88.1)
Confirmed diagnosis using a PCR test	70 (63.6)
Admitted to hospital for acute management	27 (24.5)



**Figure 2** (A–E) Proportion of responses by level of severity for EQ-5D-5L dimensions at baseline and at follow-up (%).



## DISCUSSION

These early data describe the impact of the Your COVID Recovery<sup>®</sup> digital programme on the first cohort of patients to complete the programme. The outcome data are promising and should encourage increasing access to the programme. We recognise that these data are observational and a prospective trial with a control group is required to draw definitive conclusions of effectiveness.

Data for the two outcome measures reported (EQ-5D-5L and CAT) reflected that there was an improvement in participants' perception of their overall health quality of life and are of a similar magnitude to the data reported describing a comprehensive face-to-face COVID rehabilitation programme.<sup>11</sup> The minimum clinically important difference (MCID) for these measures is yet to be established for long COVID; however, the changes seen exceed the MCID for chronic obstructive pulmonary disease.<sup>12–14</sup> There has been a randomised controlled trial reported from China<sup>5</sup> deploying a telehealth model of care which investigated a telerehabilitation programme delivered with a smartphone and heart rate monitoring. The authors reported significant improvements in exercise capacity as their primary outcome, but also reported significant outcomes in health-related quality of life measured with the SF-36 (36-Item Short Form Health Survey). There are also ongoing studies examining digital interventions.<sup>15</sup>

Moreover, previous research has reported on the lack of natural recovery for patients with long COVID using the EQ-5D-5L.<sup>2</sup> Thus, the results are encouraging for such a 'light-touch digital recovery programme' and may provide a viable solution for a number of healthcare professionals to deliver a management strategy on a larger scale. The Your COVID Recovery<sup>®</sup> digital programme offers free training for staff to help manage a cohort of patients through the digital platform. It is recommended that staff regularly contact participants to support them through the programme and troubleshoot any clinical or technical issues. We do not have data on the level of support provided to participants. The duration on the programme was variable; however, for such a low maintenance programme, this is not such a challenge in terms of capacity management. It is reasonable to expect individuals suffering from a multitude of symptoms that may fluctuate in number and severity, to take longer to work through a programme, particularly if it is largely self-directed compared with the clearly defined duration of either pulmonary or cardiac rehabilitation. One advantage, however, is that individuals have access to the site for up to 12 months post-completion of stage 4 (where the outcome measures are embedded), which is important given the fluctuating nature of symptoms previously reported. However, the data in this study are uncontrolled and a randomised controlled trial of the Your COVID Recovery<sup>®</sup> digital platform versus best usual care would be important. Future research should consider this. Nevertheless, the early data should be viewed positively and we would encourage healthcare

professionals to consider offering this low maintenance platform to individuals suffering with long COVID.

## CONCLUSION

These early data are encouraging as it demonstrates improvements in symptoms after a COVID infection following a light touch intervention, which can be offered at scale.

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**Author contributors** PHIL-E (guarantor): completed data collection/analysis and prepared the manuscript. MMB, ED, SJS: made significant contributions to analysis and manuscript development. MMB, ED, AH, GM, EC, ACNG, NG, SJS: reviewed and approved the final manuscript.

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**Competing interests** None declared.

**Patient and public involvement** Patients and/or the public were involved in the design, conduct, reporting or dissemination plans of this research. Refer to the Methods section for further details.

**Patient consent for publication** Not applicable.

**Ethics approval** This study involves human participants but was exempted. Healthcare providers signed a Digital Protection Agreement which states that only anonymous data will be used for the purpose of service evaluation. The purpose of service evaluation is to evaluate the effectiveness of the Your COVID Recovery<sup>®</sup> digital programme. Moreover, the purpose of processing this information is to observe, analyse and record on a structured online rehabilitation programme for patients diagnosed with COVID or suspected COVID. Participants gave informed consent to participate in the study before taking part.

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**Data availability statement** All data relevant to the study are included in the article or uploaded as supplementary information.

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