NHS National Services Scotland

NHS Scotland Service Evaluation of Long COVID Services

March 2024

CONTENTS

NHS SCOTLAND SERVICE EVALUATION OF LONG COVID SERVICES USING ELAROS DATA

NHS National Services Scotland (NSS) commissioned the University of Leeds to evaluate patient outcomes in those accessing NHS Long COVID (LC) clinical services in Scotland. The ELAROS Digital Patient Reported Outcome Measures (DPROMs) platform for recording outcome measure data was used to measure patient outcomes.

The aims of this baseline service evaluation were to:

a) the extent of symptom burden and functional disability in individuals accessing care in NHS-funded LC services in Scotland; and

b) where data were available, the extent of change in the severity of the condition for individuals receiving care from these services.

This report provides baseline data from LC services in Scotland. It outlines the data collection methods, participants, PROM data analysis, and interpretation of results from over a short period of time. The report also describes the limitations in interpreting the results and makes recommendations for future work to be undertaken by NHS Services in Scotland, LC services, local commissioners, and individuals with LC.

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Detail

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ABBREVIATIONS

BMI	Body Mass Index
C19-YRS	C19-Yorkshire Rehabilitation Scale
C19-YRSm	Modified C19-Yorkshire Rehabilitation Scale
CSO	Chief Scientist Office
CI	Confidence Interval
COPD	Chronic Obstructive Pulmonary Disease
EQ-5D-5L	EuroQol Five Dimensions Five Levels
FD	Functional Disability (C19-YRS)
HRA	Health Research Authority
ICU	Intensive Care Unit
LC	Long COVID
MS	Multiple Sclerosis
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NIHR	National Institute for Health and Care Research
NSS	National Services Scotland
OH	Overall Health (C19-YRS)
OS	Other Symptoms (C19-YRS)
PCS	Post-COVID Syndrome
PCC	Post-COVID Condition
PHS	Public Health Scotland
PROM	Patient Reported Outcome Measure
SD	Standard Deviation
SIMD	Scottish Index of Multiple Deprivation
SRM	Standardised Response Mean
SS	Symptom Severity (C19-YRS)
UKRI	UK Research and Innovation
VAS	Visual Analogue Scale
WHO	World Health Organisation

SUMMARY

- **Patient characteristics:** Data from 701 patients across NHS LC sites were analysed. The patient sample had a female: male ratio of 2:1, and the average age of respondents was 52.4 years. A third of patients did not have an ethnicity recorded. Of those with an ethnicity recorded, most patients were White (65%), 2.2% were Asian or mixed, and none were Black.
- **Comorbidities and pre-existing conditions:** Patients reported a high burden of co-morbidities (38%) prior to contracting COVID. However, more than half of patients had no pre-existing conditions.
- **Duration of LC:** The average duration of LC symptoms in patients seen at first assessment was 588 days (>19 months), with symptoms still ongoing at presentation.
- **PROMs:** The C19-YRS is a condition-specific PROM for LC while the EQ-5D-5L is a generic PROM for measuring an individual's health status. Both PROMs were available in the ELAROS digital tool, and a total of 1,877 PROMs were completed.
- **New-onset disability and comparison with other conditions:** 691 patients who completed at least one C19-YRS questionnaire at first assessment showed significant new-onset symptom burden, functional disability, and deterioration of overall health since contracting COVID. The cross-sectional EQ-5D index value of 562 patients suggests the burden and disability in LC are worse than that reported in the literature for Diabetes Mellitus, Chronic Obstructive Pulmonary Disease, Heart Failure, and Multiple Sclerosis.
- **Three-month follow-up:** Among those who completed an initial C19-YRS assessment and another at 3 months, there was an improvement in symptom burden, functional disability, and overall health. Patients at 3 months, however, still had significant new-onset LC symptom burden and disability compared to their pre-COVID-19 health status, i.e., their condition had improved but they were far off from complete recovery. Among those who completed EQ-5D-5L, at first assessment and at 3 months, their EQ-5D-5L index score did not show any improvement (slight deterioration) but the EQ-5D-5L VAS showed a small improvement.

- **Six-month follow-up:** Among those who completed measures at the first assessment, 3 months, and 6 months, C19-YRS and EQ-5D-5L VAS showed significant improvement whereas EQ-5D Index Value showed a significant deterioration. Patients at 6 months, however, still had significant new-onset LC symptom burden and disability compared to their pre-COVID-19 health status, i.e. their condition had improved but had not achieved complete recovery.
- **C19-YRS vs EQ-5D-5L:** The 6-month follow- up changes in scores indicate that C19-YRS Symptom Severity domain is a more sensitive measure than EQ-5D-5L in LC. This is in keeping with the literature recommending the use of condition-specific measures.
- **Vocational problems:** 70% of this sample had their work role affected with them having to either be on sick leave, reduce hours, change roles, or quit roles. Only 14% were able to maintain roles they had held prior to their COVID-19 infection. This is suggestive of considerable productivity loss and financial implications to the country.

INTRODUCTION

Long COVID (LC) or Post-COVID Syndrome or Post-COVID Condition is a clinical syndrome of persistent symptoms after a confirmed or probable COVID-19 infection. LC is a patient-derived term1 used broadly for symptoms persisting more than 4 weeks after the infection, whereas Post-COVID Syndrome or Post-COVID Condition are scientific terms used by NICE and WHO respectively for symptoms persisting beyond 12 weeks.2,3

Figures of LC prevalence in Scotland vary. One cohort study estimated the prevalence to be 6% while another population-based study reported up to 1.8% of the population being affected.5,6 The National Institute for Health and Care Research (NIHR) and UK Research and Innovation (UKRI) have so far invested over £50 million in more than 20 LC studies.7 In addition, the Scottish Government's Chief Scientist Office has awarded over £3 million for 11 projects on the long-term effects of COVID-19. Research ranges from studies to better understand the epidemiology and pathophysiology of LC, as well as trialling possible treatments and interventions to support patient recovery.

Scotland has also invested £10 million into its LC services. It is therefore important to assess patient outcomes in those accessing these services, particularly if we are to ensure they are providing patients with the support they need. Undertaking a baseline evaluation may also assist with future service planning as well as potentially identify transferable learning for managing other long-term conditions.

The digital platform ELAROS was procured by National Services Scotland on behalf of Scotland's LC network. 8 The platform allows patients to record Patient Reported Outcome Measures (PROMs). PROMs assess the quality of care delivered to NHS patients from the patient perspective.

The ELAROS platform was first implemented in NHS Highland and NHS Lanarkshire's LC services in 2022 before being adopted by more Health Boards in October 2023. The digital platform is available for any NHS Health Board to use following approval from their local information governance department. At the time of this report, data were only available from 8 Health Boards across 20 localities in Scotland. A key limitation of this report is that the collection and analysis of PROM data was undertaken very close to the start of Health Boards adopting the digital tool.

METHODS

The ELAROS Patient Reported Outcome Measure (PROM) platform comprises a digital application (app) available on mobile, web, or via telephone appointment for patients to complete PROMs pre- configured by an NHS Long COVID service; to monitor their progress; communicate with staff, and access support resources relevant to them for a range of symptoms.

Following referral to a Long COVID service, patients are registered onto the digital platform by clinical teams providing them with care via an online web portal which generates a unique set of login details for the patient to access the app remotely, independently, or with support from a clinician or relative.

Data collected via the app are automatically sent to the web portal securely and in real-time to a segregated virtual centre for clinical staff to view: responses, message patients, request follow-up assessments, and analyse data at an individual and cohort level over time.

Patients are routinely asked to provide consent to sharing particular pseudonymised data for the purpose of service audits and evaluations via the app. Permitted data is then shared in pseudonymised format with University of Leeds who can view and extract the filtered raw data for analysis from an alternative version of the web portal.

Ethical considerations

This project aims to measure current practice and is defined as a service evaluation, as assessed by the Health Research Authority (HRA) 'Is my study research?' tool and approved by NHS National Services Scotland. It therefore does not require NHS REC review, as assessed by the HRA 'Do I need NHS REC review' tool. The knowledge gleaned from the service evaluation will be used to produce recommendations for improvement, inform change, and demonstrate achievements and challenges.

Instruments

PROMs used on the ELAROS platform were the C-19 YRS and the EuroQol EQ-5D-5L.

C19-YRS

The COVID-19 Yorkshire Rehabilitation Scale (C19-YRS) PROM was specifically developed to measure the symptoms, functioning and disability associated with COVID-19.[10] The C19-YRS (original) comprises 22 items each rated on an 11-point numerical rating scale from 0 (none of this symptom) to 10 (extremely severe level or impact). The instrument has four subscales (range): Symptom Severity score (0–100), Functional Disability score (0–50), Additional symptoms (0–60), and Overall Health (0–10). The C19-YRS was the first condition-specific PROM to be validated in LC and has been shown to be reliable and have appropriate psychometric properties to be used in this population.[11] C19-YRSm is a modified version of the original C19-YRS with a 4-point response category: 0, no problem to 3, severe problem.[12] As with the unmodified

'original C19-YRS' instrument there are four subscales (range): Symptom Severity (0-30), Functional Disability (0-15), Other Symptoms (0-25), and Overall Health (0-10). Although the C19-YRSm was derived from the original version of the instrument the subscales are not fully compatible and there is, as yet, no algorithm to equate the two measures.

C19-YRSm is the current version used across health services for this study and is generally referred to as the C19-YRS. The self-reported PDF version for NHS use has been included in Appendix A.

EQ-5D-5L

The EQ-5D-5L is a concise, generic measure of self-reported health which is accompanied by weights reflecting the relative importance to people of different types of health problems. It has five single-item domains: Mobility, Usual Activities, Selfcare, Pain/Discomfort, and Anxiety/Depression. It has five response categories ranging from 1 (no problems) to 5 (severe problems). Responses to each domain are collated into a profile score which is converted into a health utility or index score using a country-specific algorithm (tariff or value set). Utilities reflect societal preferences for health states and are measured on a metric from 0 (dead) to 1 (perfect health). Utility values less than 0, indicating states worse than dead, are also captured. The EQ-5D-5L were mapped onto the EQ-5D-3L (an alternative version of the instrument with 3 response categories advocated by the National Institute for Health and Care Excellence, NICE) using the van Hout et al. (2012) mapping (crosswalk or CW) algorithm to derive UK utility values.[13] The EQ-5D Visual Analogue Scale (VAS) is a component of the EQ-5D: respondents are asked to rate their overall current health ("today") on a scale from 0 ("worst possible") to 100 ("best possible"). A copy of the EQ-5D is available from the developer's website (euroqol.org).

Data Import, Cleaning and Coding

The data were downloaded in three batches from the ELAROS platform on 15 February 2024. No restrictions were placed on the earliest date of registration on the platform. The three batches corresponded to each of the PROMs: Original C19-YRS, C19-YRSm and the EQ-5D-5L. The downloaded files were stored as comma separated values (csv) files (in MS Excel). Each dataset was imported separately into R-studio (version 2022.07.2) for data cleaning and analysis.

NB: The original version of the C19-YRS had only been completed by 2 patients (single completion by 2 patients at NHS Highland Long COVID Service) and therefore no further analysis was undertaken on this dataset.

Each patient was allocated a unique 13-character patient identification (ID) number. The last 2 to 3 digits in this ID number represented a cumulative total of the number of completions of the PROM. This number was independent of the assessment time, e.g., successive totals may represent a PROM being completed on either the same assessment day or successive days. These digits were extracted from the patient ID

and stored as a variable recording the number of PROMs completed.

The assessment time was stored as a composite of date (day/month/year; dd/mm/yyyy). The date component was extracted and stored as a separate assessment date variable. A variable was derived for cumulative time by calculating the time difference in days between successive completed assessments. This cumulative time variable ranged from 0 to N days.

The cumulative time between successive assessments was used to categorise the data into a 90-day period after the first assessment allowing for 30 days either side of the 90-day midpoint; in other words, a time period from 60 to 120 days after the first assessment. The same principle was used to derive a 180-day period after the first assessment ± 30 days (i.e. 150 to 210 days after the first assessment). These two timepoints were used in the longitudinal analysis described below (*Statistics*).

The time from the occurrence of the first COVID symptoms to a) first assessment and b) registration was calculated for each patient. As the infection date was occasionally recorded to a default setting of 01.01.1970, this meant that some values for both the time to first assessment and registration were erroneous. These times were excluded in the analysis by recoding the times as missing data.

The domains for the C19-YRSm (Symptom Severity, Functional Disability, Overall Health and Other Symptoms) and the EQ-5D-5L (Mobility, Selfcare, Usual Activities, Pain/Discomfort and Anxiety/Depression) were recoded into a numeric format (from character format). The same was also applied to the variables for: age, height, weight, admission days and Intensive Care Unit days. Age was restricted to the adult population, i.e., age ≥ 18 years. Mis-recorded age values (negative values or age >120 years) were removed from the analysis.

Index scores were derived for the EQ-5D-5L using the van Hout et al. crosswalk algorithm[13] (EQ-5D- 5L CW) to map the profile scores onto the EQ-5D-3L (for compatibility with the other EQ-5D data sources and preferred by the National Institute for Health and Care Excellence, NICE), as well as the EuroQol Valuation Technology algorithm[14] (EQ-5D-5L VT). The “eq5d” library (in R) was used to derive these indices.

Records from the English and Welsh centres in the datasets were removed.

The Scottish Index of Multiple Deprivation (SIMD) quintiles were derived from the most recent postcode data (2020v2), where available, using the Scottish Government’s online tool: **https://www.gov.scot/collections/scottish-index-of-multiple-deprivation-2020/**. SIMD ranks data zones from most deprived (ranked 1) to least deprived (ranked 6,976) and were presented as quintiles (quintile 1 is most deprived, quintile 5 is least deprived).

Pre-COVID comorbidities had been recorded in a single cell for each patient. The cell was split to create a binary coded variable (yes/no; 1/0) for each of the following comorbidities: respiratory, mental health, cardiovascular, diabetes, and other, as well as none.

Body Mass Index (BMI) was calculated using the standard formula namely, weight in

kilograms divided by the square of height (measured in metres). BMI values exceeding the extremes for published data in the UK population were excluded from the analysis i.e. BMI <11 or >59.

Statistical Methods

Continuous data (e.g. age, BMI) were summarised using means and standard deviations.

95% confidence intervals were included for the PROMs (original C19-YRS, C19-YRSm and EQ-5D-5L scores).

SIMD quintiles were summarised using medians and range (minimum to maximum), with SIMD quintile 1 representing the most deprived and SIMD quintile 5 the least deprived. Categorical variables (e.g. ethnicity, smoking and occupational status) were described using totals and percentages. The data were broken down to produce summaries per Board, as well as an overall summary. No formal statistical testing was undertaken on these data.

Changes over time were assessed for the C19-YRSm scores and the EQ-5D-5L Index and Visual Analogue Scale (VAS) for those patients who had completed the first assessment and the 90-day assessment, and additionally for those who had completed an assessment at 180 days (± 30 days). The standardised response mean (SRM) – an effect size measure - was derived to evaluate the relative responsiveness (i.e. the ability of the instruments to respond to or detect change over time) of the C19-YRSm and the EQ-5D-5L Index and VAS for those patients who had completed the two PROMs on the same day. The SRM was calculated as the difference in scores on the C19-YRSm domains (Symptom Severity, Functional Disability, Overall Health and Other Symptoms) and EQ-5D-5L index and VAS between day 90 (± 30 days) and the first assessment divided by the standard deviation of the score difference.

Regression analyses were undertaken to evaluate the predictors for the changes in the domain of Symptom Severity over time. Given the potential differences between patients at first assessment (in terms of Symptom Severity scores) and differences in how individual symptom trajectories could evolve over time, linear mixed effects models were applied with random intercepts and slopes. The *lme4* library was used for this analysis. The following variables were considered for inclusion as covariates in the analysis: sex (male/female), age group (categorised as: 18-39, 40 to 49, 50 to 59, and 60 years and over); ethnicity (White, Black, Asian, Mixed and Other); duration of symptoms; hospital admission (yes/no); ICU admission (yes/no); total pre-COVID comorbidities; co-morbidities (respiratory, mental health, diabetes, cardiovascular, none); and Health Board. SIMD was not included, as this could potentially distort the associations between co-morbidities and outcomes or ethnic group and outcomes. Interactions between covariates and time were also derived. For ease of interpretation the regression slopes over time are presented as the change in symptom scores per 90 days.

A provisional analysis of non-active responders was also undertaken. Given the short nature of the study period, non-active responders are defined here as participants who only completed the C19-YRSm once during the study period. A binary logistic regression analysis was undertaken to evaluate potential predictors of non-active responders. These covariates included: age, gender, infection time, (from the C19-YRSm) Symptom Severity, Functional Disability, Overall Health and Other Symptoms.

As a reporting convention, all sociodemographic (where applicable) and C19-YRSm results (including, mean, standard deviation and 95% confidence intervals) were reported to one decimal place; results for the EQ-5D-5L Index and regression parameters (and 95% confidence intervals) were reported to two decimal places.

RESULTS

Demographic characteristics of people attending LC services

Table 1 provides the demographic characteristics of the patients who registered on the ELAROS system. A total of 701 patients registering across 8 participating Health Boards also gave consent to sharing their data for the service evaluation. The majority of patients registered on the app came were being seen by Lanarkshire and Highland.

The mean age of the overall patient sample was 52.4 years, and two thirds were female (67%).

The main recorded ethnicity was White (65%) with the second largest recorded ethnicity being Asian (1%). Ethnicity had not been recorded for 33% of the sample. The mean duration of LC or time since first infection was 588 days. This ranged for the two Boards that recorded sufficient numbers for this information from 441 days (NHS Highland Long COVID Service) to 624 days (COVID Rehabilitation Team NHS Lanarkshire).

Most patients had not been hospitalized with COVID. For the 12% of the patients reporting a hospital admission, the mean duration of stay was 13.4 days. Only 4.6% of the sample had been admitted to an intensive care unit (ICU) with a mean duration of 14.6 days.

Over a third of patients had pre-COVID comorbidities (38%). The proportion reporting post-COVID comorbidities was higher at 43%.

13% of patients had respiratory comorbidities (pre-COVID, N=88); 15% mental health problems (N=108); 5% (N=33) cardiovascular problems; 5% (N=34) diabetes and 17% (N=120) other pre-COVID comorbidities.

Smoking status was not reported for 56% of patients. The remaining 29% of the patient sample reported they had never smoked, 11% were ex-smokers and 4% reported being current or occasional smokers.

Body mass index (BMI) was only available for 111 patients. This low number is largely due to a combination of missing and miscoded data for either the height or weight variables or both. Of those with a BMI recorded, the mean BMI was 31.1 kg/m^2 and 56% (63 patients) were obese (BMI ≥ 30 kg/m^2).

Postcodes were only available for 290 patients (41%) which was required to derive SIMD. The median SIMD quintile was 3.

Table 1. Demographics by Health Board

Variable	Overall, N = 701	COVID Rehab Team NHS Lanarkshire, N = 454	NHS Highland Long COVID Service, N = 169	Other Boards (GGC, A&A, FV, D&G, Borders, Tayside) N = 78
Female	468 (67%)	309 (68%)	104 (62%)	55 (71%)
Male	233 (33%)	145 (32%)	65 (38%)	23 (29%)
Mean age (years, SD)	52.4 (14.0)	53.7 (13.7)	50.5 (14.6)	Mean age range: 43.8-54
Discharged (Yes)	12 (1.7%)	2 (0.4%)	10 (5.9%)	0 (0%)
Time to discharge (days, SD)	175.1 (60.5)	214.0 (86.3)	169.2 (58.0)	NA
Ethnicity*				
White	458 (65%)	353 (78%)	98 (58%)	3
Asian	7 (1.0%)	4 (0.9%)	3 (1.8%)	0
Other ethnic	3 (0.4%)	2 (0.4%)	1 (0.6%)	0
Mixed or multiple ethnic	3 (0.4%)	2 (0.4%)	1 (0.6%)	0
Not recorded	230 (33%)	93 (20%)	66 (39%)	64 (82%)
Smoking status (N=308)				
Never smoked	202 (29%)	187 (41%)	15 (8.9%)	0 (0%)
Ex-smoker	79 (11%)	71 (16%)	8 (4.7%)	0 (0%)
Current regular smoker	15 (2.1%)	14 (3.1%)	1 (0.6%)	0 (0%)
Current occasional smoker	12 (1.7%)	10 (2.2%)	2 (1.2%)	0 (0%)
BMI recorded (kg/m2) (N=111)	31.1 (7.1)	31.3 (7.2)	28.5 (5.7)	NA
Obesity (N=111)	63 (56%)	59 (57%)	4 (50%)	0 (NA%)
Time since first infection (days, SD) (N=461)	587.9 (346.3)	623.9 (348.1)	440.6 (298.5)	NA

Variable	Overall, N = 701	COVID Rehab Team NHS Lanarkshire, N = 454	NHS Highland Long COVID Service, N = 169	Other Boards (GGC, A&A, FV, D&G, Borders, Tayside) N = 78
Hospital admission (Yes) (N=83)	87 (12%)	78 (17%)	9 (5.3%)	0 (0%)
Admission duration (days, SD)	13.4 (16.6)	13.7 (17.2)	10.7 (9.1)	NA
ICU admission (N=32)	32 (4.6%)	28 (6.2%)	4 (2.4%)	0 (0%)
Duration in ICU (days, SD)	14.6 (12.8)	15.3 (13.4)	10.3 (5.9)	NA
Pre-COVID comorbidities				
None	432 (62%)	210 (46%)	144 (85%)	78 (100%)
1	176 (25%)	160 (35%)	16 (9.5%)	0 (0%)
2+	93 (13.2%)	84 (18%)	9 (5.3%)	0 (0%)
Post-COVID comorbidities				
None	398 (57%)	177 (39%)	143 (85%)	78 (100%)
1	163 (23%)	149 (33%)	14 (8.3%)	0 (0%)
2+	140 (20.1%)	128 (28.4%)	12 (7.1%)	0 (0%)
CV-19 variant (N=365)				
Alpha	60 (16%)	53 (18%)	7 (9.6%)	0 (NA)
Delta	48 (13%)	44 (15%)	4 (5.5%)	0 (NA)
Omicron	208 (57%)	154 (53%)	54 (74%)	0 (NA)
Original	49 (13%)	41 (14%)	8 (11%)	0 (NA)
Total PROMs per patient				
1	578 (82%)	428 (94%)	86 (51%)	63 (81%)
2	61 (8.7%)	22 (4.8%)	28 (17%)	11 (14%)
3+	62 (9.0%)	4 (0.9%)	55 (32%)	2 (3%)

‡To maintain anonymity, some data for Boards has been aggregated.
NA: Not Applicable; SD: standard deviation; IQR: interquartile range (25th and 75th centile); ICU: intensive care unit; PROMs: patient-reported outcome measures.
*White (includes any white background); Asian (includes any Asian background, for example, Bangladeshi, Chinese, Indian, Pakistani); Another ethnic group (includes any other ethnic group, for example, Arab); Mixed or multiple ethnic groups (includes any mixed background)

Patient Reported Outcome Measures (PROMs)

A total of 1,877 patient-reported outcome measure (PROM) measurements had been completed: 59% (N=1111) C19-YRSm and 41% the EQ-5D-5L (N=766).
The C19-YRSm scores at the first assessment are shown in Table 2a. It may be seen from this Table that there was a large degree of "missing" data, particularly for the "Pre" COVID scores on that instrument and especially for the Functional Disability domain (e.g. 64%).

Table 2a. Overall C19-YRSm unadjusted scores at first assessment

Characteristic, N = 691	Pre score Mean (SD)	95% CI	Now score Mean (SD)	95% CI
Symptom Severity (scale 0-30) (Missing pre:140)	5.8 (4.7)	5.5, 6.2	20.6 (5.4)	20, 21
Functional Disability (scale 0-15) (Missing pre:440, now:5)	3.7 (3.2)	3.3, 4.1	8.7 (3.7)	8.4, 9.0
Overall Health (scale 0-10) (Missing pre: 96, now: 3)	7.4 (2.5)	7.2, 7.6	4.0 (2.0)	3.8, 4.1
Other Symptoms (scale 0-25) (Missing now: 46)	-	-	7.6 (4.5)	7.3, 8.0

SD: Standard Deviation. CI: Confidence Interval

*At first assessment, the C19-YRSm records Symptom Severity (higher score more severe), Functional Disability (higher score more disability), Other Symptoms (score indicates number of other symptoms), and Overall Health (lower score, poorer health) for both pre- COVID and current status. However, pre-COVID scores are not recorded for 'Other Symptoms'.

The missing data affected two Health Boards primarily: COVID Rehabilitation Team NHS Lanarkshire and NHS Highland COVID Recovery Service which supported a combined 88.9% (n=623) of the overall patient sample (n=701). Six items were

selected from the C19-YRSm to review missingness, namely: Breathlessness, Fatigue, Palpitations, Malaise, Communication and Personal Care. The level of missingness was consistent across these items for the “Pre” COVID scores, ranging from 13-16% for NHS Lanarkshire and 6-8% for NHS Highland suggesting that no specific items were particularly affected. Given that missingness mainly affected the “Pre” COVID responses, that there was no forced response in place for the items on the C19-YRSm, and that patients were able to skip responses to the items, we speculated that the missing data reflected patients not answering the questions as the items were either not relevant or did not present problems to the patient. Consequently, we made this assumption in the modelling, therefore the missing values were replaced with a zero (“no problem”) and the domain scores recalculated to create adjusted scores in Table 2b. All adjusted domain scores subsequently decreased compared to the unadjusted scores, particularly all the pre-COVID and the Functional Disability domains.

Table 2b. Overall adjusted C19-YRSm scores at first assessment

C19-YRSm, N = 691	Pre score Mean (SD)	95% CI	Now score Mean (SD)	95% CI
Symptom Severity (scale 0-30)	4.3 (4.5)	4.1, 4.6	19.7 (5.4)	19, 20
Functional Disability (0-15)	1.2 (2.4)	1.0, 1.3	8.7 (3.7)	8.4, 9.0
Overall Health (0-10)	6.4 (3.5)	6.1, 6.6	4.0 (2.0)	3.8, 4.1
Other Symptoms (0-25)	-	-	7.0 (4.7)	6.8, 7.3

SD: Standard Deviation. CI: Confidence Interval

Table 2b demonstrates the impact of LC on patient health with a substantial worsening, from the pre-COVID ratings, at first assessment for Symptom Severity, Functional Disability and Overall Health.

As noted in Table 1, there were 61 patients with a second assessment. However, only 26 patients had completed the second C-19 YRSm assessment at 90 days (± 30

days). These data are shown in Table 3a. There was a two-point reduction in scores on the Symptom Severity domain suggesting an improvement over time; similarly there was roughly a 0.5-point decrease in Functional Disability again indicating improvement. Other Symptoms had also decreased, whereas Overall Health remained unchanged.

Of the 26 patients with follow-up data, 11 had also completed another assessment by 180 days (± 30 days). These data are shown in Table 3b. For this small sample of patients, Symptom Severity had improved by almost 4 points at Day 180 (± 30 days). Functional Disability showed similar improvements. A small change was observed in Overall Health which at Day 180 had almost returned to pre-COVID levels. Other symptoms had also decreased at this timepoint.

For the EQ-5D-5L and VAS (Table 4a) data were available from 562 patients. The scores on the EQ-5D-5L and VAS were all very low reflecting poor Health-Related Quality Of Life (HRQoL). Data were available for 22 patients with follow-up data at 90 days (± 30 days) as shown in Table 4b. This subset of patients had higher HRQoL scores on the EQ-5D index at the first assessment compared to the overall sample, however, these scores decreased over time; conversely the VAS scores improved over time. Ten patients also had data from a second follow-up (at 180 days) (Table 4c). Although this sample is too small for robust conclusions it may, for instance, be seen that their EQ-5D index scores decreased in the immediate 90 days after the first assessment, then subsequently improved. The VAS scores showed the opposite effect.

The standardised response mean (SRM) for the Symptom Severity domain (response to change over a 90-day period + 30 days) was 0.46; 0.15 for Functional Disability, 0.06 for Overall Health; and 0.26 for Other Symptoms. In contrast, the SRM for the EQ-5D-5L (Index) was 0.33 and the VAS 0.10.

Table 3a. Changes in C19-YRSm scores at 90 (± 30) days follow-up assessment

C19-YRSm, N = 26	Pre-COVID (Mean, SD) [95% CI]	1st Assessment (Mean, SD) [95% CI]	2nd Assessment (Mean, SD) [95% CI]
Symptom Severity	3.3 (3.5) [1.9, 4.8]	20.2 (4.4) [18, 22]	18.2 (4.2) [17, 20]
Functional Disability	0.8 (2.0) [0.05, 1.6]	8.5 (3.9) [6.9, 10]	7.9 (3.6) [6.5, 9.4]
Overall Health	6.3 (3.9) [4.7, 7.9]	4.2 (1.7) [3.5, 4.9]	4.3 (1.6) [3.7, 5.0]
Other Symptoms		6.6 (4.2) [4.9, 8.3]	5.5 (3.5) [4.1, 6.9]

SD: Standard Deviation. CI: Confidence Interval

Table 3b. Changes in C19-YRSm scores at 180 (± 30) day follow-up assessment

C19-YRSm, N = 11	Pre-COVID score (Mean, SD) [95% CI]	1st Assessment (Mean, SD) [95% CI]	Day 90 (± 30 days) (Mean, SD) [95% CI]	Day 180 (± 30 days) (Mean, SD) [95% CI]
Symptom Severity (0-30)	2.1 (2.3) [0.55, 3.6]	20.0 (4.2) [17, 23]	17.3 (4.5) [14, 20]	15.5 (3.5) [13, 18]
Functional Disability (0-15)	0.6 (1.0) [-0.05, 1.3]	9.1 (4.0) [6.4, 12]	8.6 (4.0) [6.0, 11]	6.5 (3.6) [4.1, 8.8]
Overall Health (0-10)	5.5 (4.4) [2.5,8.4]	4.1 (2.1) [2.7, 5.5]	4.5 (2.1) [3.0, 5.9]	5.2 (1.7) [4.1, 6.3]
Other Symptoms	-	7.6 (3.1) [5.6, 9.7]	4.5 (2.7) [2.6, 6.3]	4.9 (3.8) [2.4, 7.4]

SD: Standard Deviation. CI: Confidence Interval

Table 4a. Overall EQ-5D-5L Index and Visual Analogue Scale (VAS) scores at first assessment

EQ-5D, N = 562	Score Mean (SD)	95% CI
EQ-5D-5L (CW) (Missing 4)	0.41 (0.29)	0.38, 0.43
EQ-5D-5L (VT) (Missing 4)	0.49 (0.29)	0.46, 0.51
EQ-5D (VAS) (Missing 2)	44.9 (20.0)	43, 47

SD: Standard Deviation; CI: Confidence Interval; CW: crosswalk; VT: Valuation Technology; VAS: Visual Analogue Scale

NB: Lower score indicates poorer health-related quality of life.

Table 4b. Changes in EQ-5D-5L Index and VAS scores at the 90 (± 30) day follow-up assessment (N=22)

EQ-5D, N = 22	1st Assessment Mean (SD) [95% CI]	Day 90 (± 30 days) Mean (SD) [95% CI]
EQ-5D-5L (CW)	0.53 (0.21) [0.43, 0.62]	0.46 (0.332) [0.31, 0.60]
EQ-5D-5L (VT)	0.61 (0.20) [0.53, 0.70]	0.54 (0.35) [0.38, 0.69]
EQ-5D VAS	42.8 (19.6) [34, 51]	44.8 (24.5) [34, 56]

SD: Standard Deviation; CI: Confidence Interval; CW: crosswalk; VT: Valuation Technology; VAS: Visual Analogue Scale

NB: Lower score indicates poorer health-related quality of life

Table 4c. Changes in EQ-5D-5L and VAS scores over time (180 days) (N=10)

EQ-5D, N = 10	1st Assessment Mean, (SD) [95% CI]	Day 90 (± 30days) Mean, (SD) [95% CI]
EQ-5D-5L (CW)	0.56 (0.17) [0.44, 0.67]	0.53 (0.24) [0.35, 0.70]
EQ-5D-5L (VT)	0.63 (0.15) [0.52, 0.74]	0.60 (0.24) [0.43, 0.78]
EQ-5D (VAS)	39.5 (15.2) [29, 50]	48.4 (21.0) [33, 63]

SD: Standard Deviation; CI: Confidence Interval; CW: crosswalk; VT: Valuation Technology; VAS: Visual Analogue Scale

The impact of LC on occupational status is shown in Table 5. Just under a quarter (24%) of the sample was on sick leave. 27% of patients had needed to make changes to their working arrangements or reduce their working hours, and 7% had lost their job as a result of LC.

Table 5. Occupational Status*

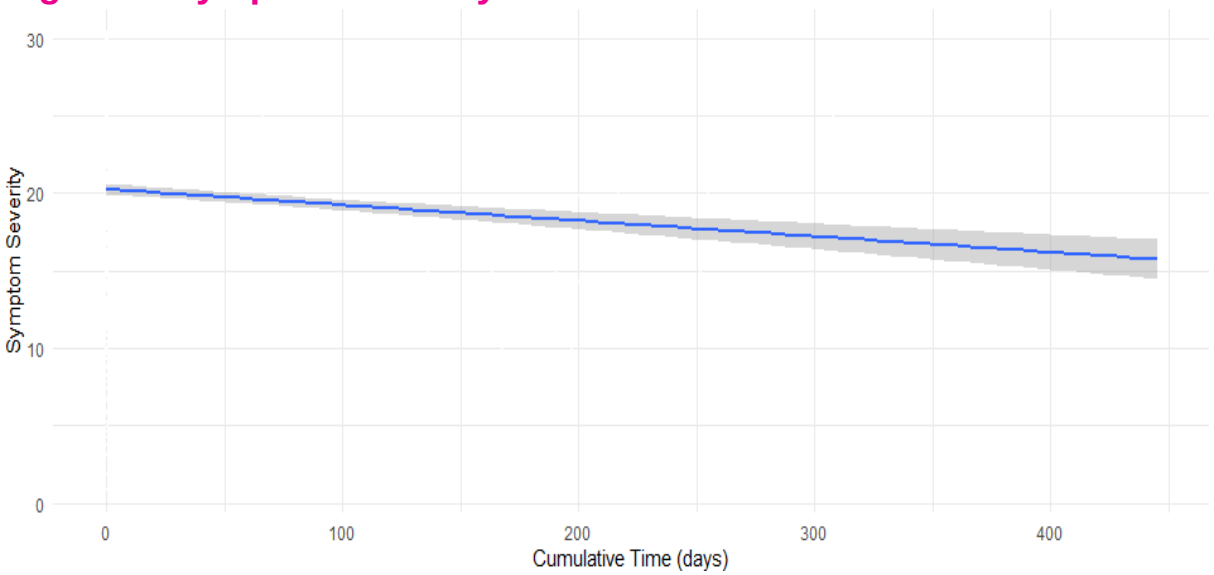
Change in occupation	N = 691 (% of patients)	95% CI
On sickness leave	168 (24%)	21%, 28%
Changes made to role/ working arrangements (such as working from home or lighter duties)	113 (16%)	14%, 19%
Had to retire/ change job	79 (11%)	9%, 14%
On reduced working hours	77 (11%)	9%, 14%
Lost job	48 (6.9%)	5%, 9%
No change	98 (14%)	12%, 17%
Not recorded	108 (16%)	13%, 19%

CI = Confidence Interval
*Taken from the original C19-YRS and C19-YRSm

Modelling symptom trajectories based on Patient Reported Outcome Measures (PROMs)

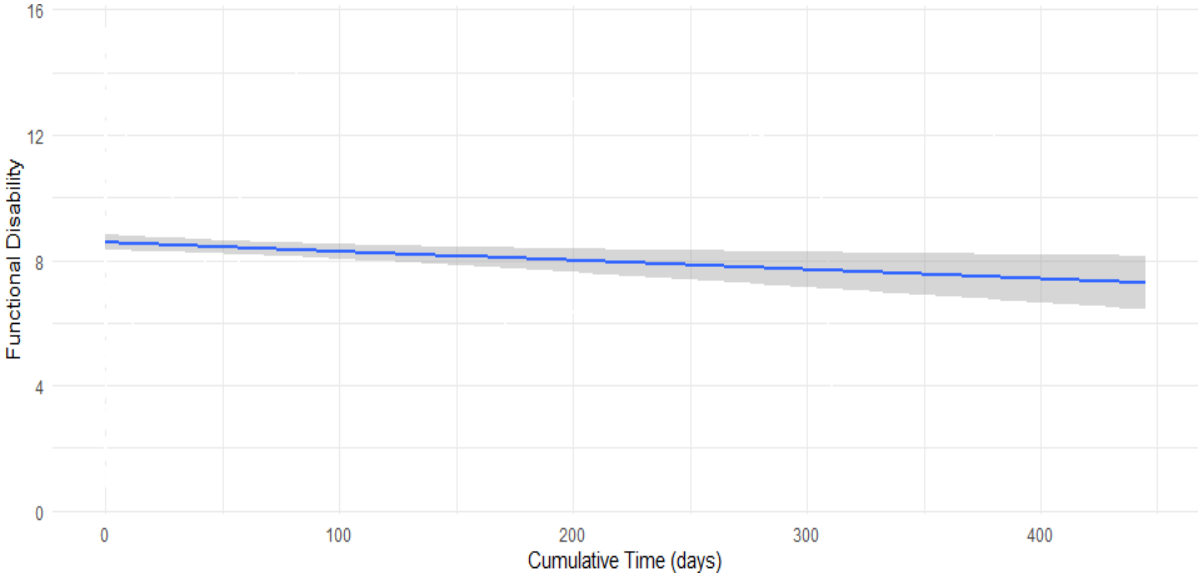
Figure 1 shows the modelled change in Symptom Severity score on the C19-YRSm over time. The (modelled) average score at the first assessment is around 21; this gradually improves over time with an average score of approximately 17 for those patients' completing assessments around day 400 after their first assessment. Longitudinal changes in Functional Disability and Overall Health are shown in Figures 2 and 3, both demonstrating more modest improvements over time. Table 6 further quantifies this improvement.

Figure 1. Symptom Severity over time



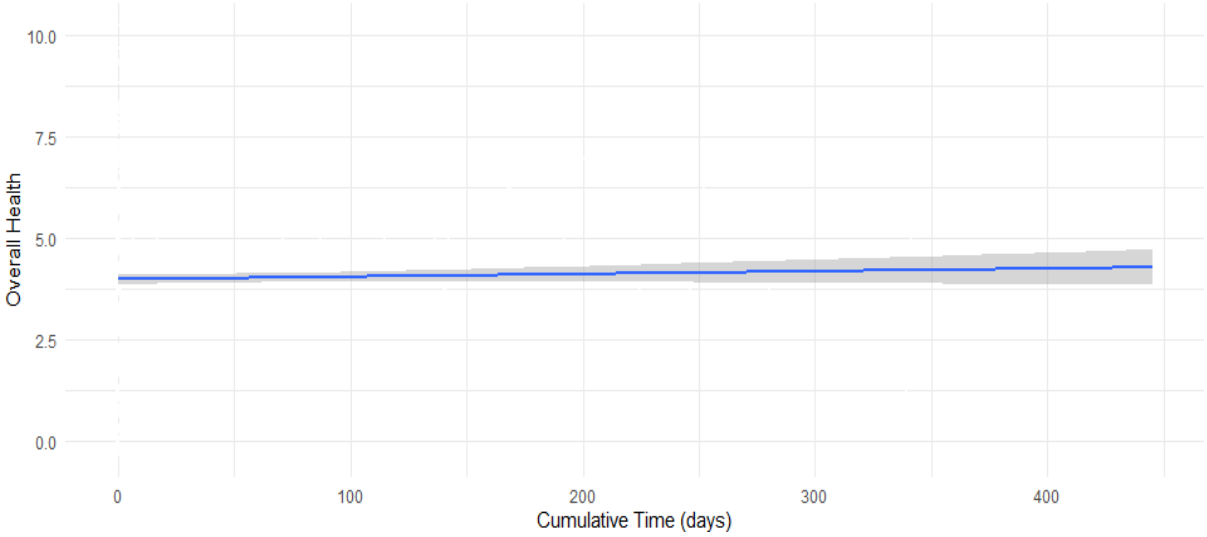
NB: The shaded area in the figures represents the standard error.

Figure 2. Functional Disability over time



NB: The shaded area in the figures represents the standard error.

Figure 3. Overall Health over time



NB: The shaded area in the figures represents the standard error.

Table 6 shows the results of the first regression model (random intercepts only, no covariates) indicating an average Symptom Severity score of 20.6 at first assessment ("intercept"). The cumulative time predictor indicates that over a 90-day period the Symptom Severity score will improve, on average, by roughly 1 point (negative values indicate a lessening in severity). Similarly, over 180 days, Symptom Severity will improve on average by approximately 2 points. This is in the context of a total Symptom Severity score that can range from 0 to 30.

Table 6. Random intercepts model / random slopes model for Symptom Severity

Predictors	Estimates	95%CI
Change in Symptom Severity per 90 days **unadjusted** for covariates*	-0.99	-1.35 to -0.54
Change in Symptom Severity per 90 days **adjusted** for covariates*	-0.63	-1.17 to 0

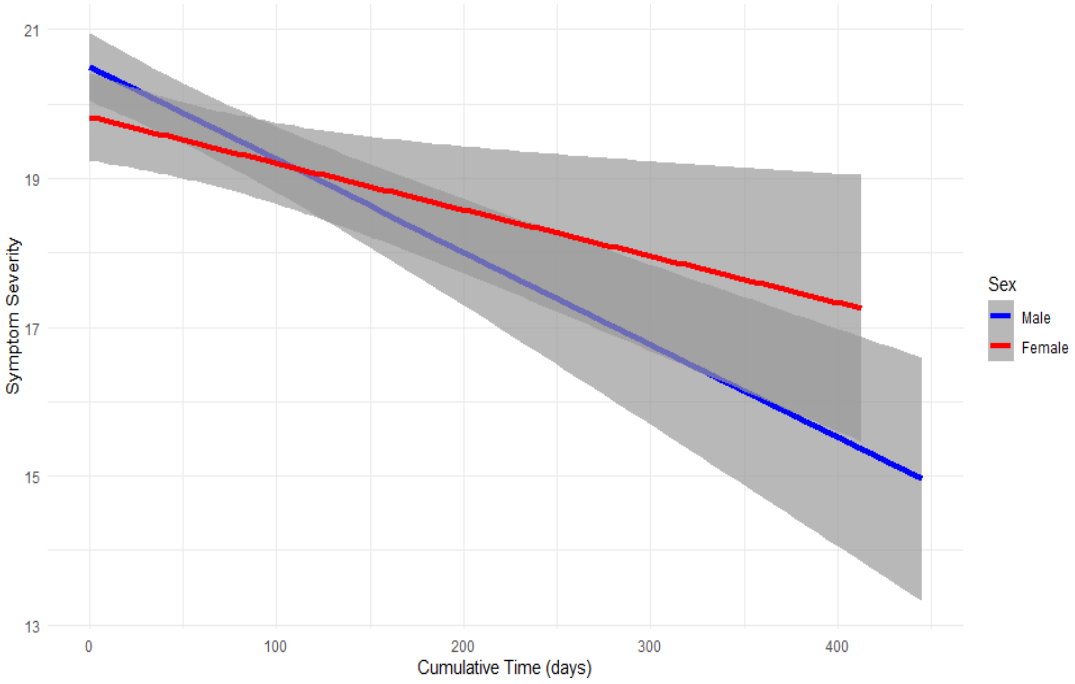
*Cumulative time from 1st assessment multiplied by 90 to provide an indication of change over 90 days. CI: Confidence interval.

Covariates: Sex, Age, Pre-COVID Co-morbidity, Ethnicity

Symptom trajectory subgroup analyses

The Symptom Severity score trajectories over time, separated by sex, are shown in Figure 4. Whilst male patients had, on average, worse Symptom Severity scores at the first assessment compared to females, and both males and females improved, there was a suggestion that males may see slightly better improvement (lowering of Symptom Severity scores) compared to females over the course of time. These differences, however, were not statistically significant (p=0.59, Table 7) when symptom trajectories for males and females were formally compared.

Figure 4. Symptom Severity over time by sex



NB: The shaded area in the figures represents the standard error.

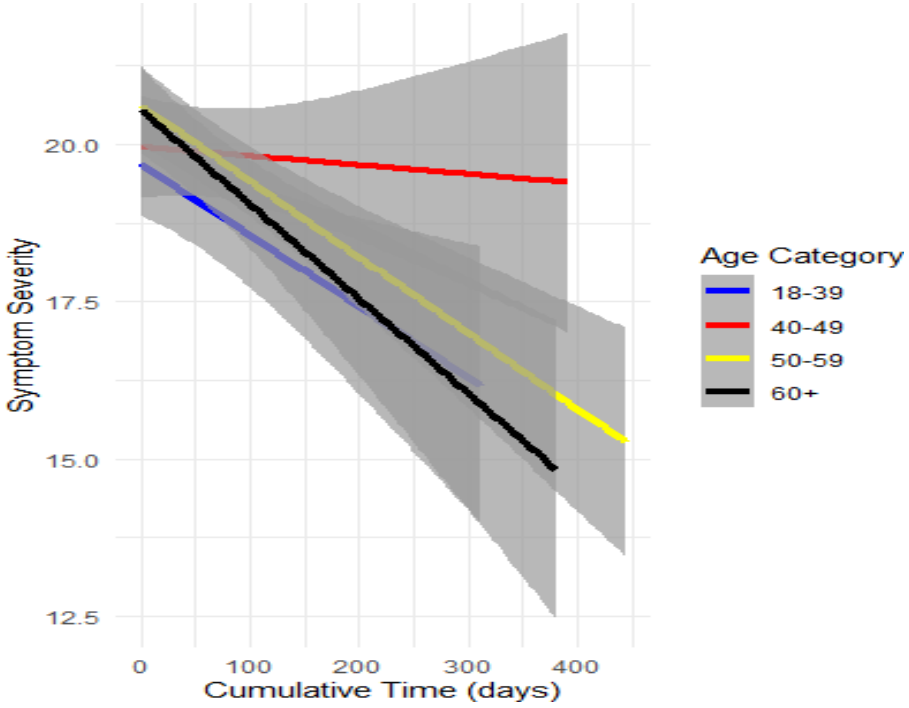
Table 7. Random intercepts and slopes model for Symptom Severity (with covariates and interaction terms)

Interactions	Estimates	CI	p-value for the interaction
Time			
≤90 days from 1st assessment	-1.66	-2.75 – -0.59	0.022
>90 days from 1st assessment	-0.20	-0.90 – -0.51	
Sex			
Male	-0.83	-1.58 – -0.54	0.59
Female	-1.07	-1.51 – -0.14	
Age			
18-39 years	-0.81	-1.90 – 0.28	0.58
40-49 years	-0.47	-1.39 – 0.46	
50-59 years	-1.16	-1.82 – -0.49	
60+ years	-1.25	-2.07 – -0.44	
Pre-existing respiratory problem			
No	-1.05	-1.49 – -0.61	0.45
Yes	-0.59	-1.70 – 0.53	
Hospital admission			
No	-1.10	-1.52 - -0.68	0.08
Yes	0.14	-1.17 - 1.44	
ICU admission			
No	-1.06	-1.47 - -0.66	0.06
Yes	0.88	-1.10 – 2.85	
Pre-existing mental health problem			
No	-1.01	-1.47 – -0.55	0.81
Yes	-0.87	-1.86 – 0.12	
Pre-existing cardiovascular problem			
No	-0.99	-1.41 – -0.56	0.98
Yes	-0.97	-2.74– 0.80	
Pre-existing diabetes			
No	-0.95	-1.18 – -0.73	0.19
Yes	-0.28	-1.31 – 0.75	
Other pre-existing health problems			
No	-0.97	-1.42 – -0.53	0.91
Yes	-1.04	-2.12 – 0.03	
Board - Results not included			
Ethnicity			
Asian	-1.17	-4.35 – 2.01	0.99
Black§	-	-	
Mixed	-0.66	-3.63 –2.30	
White	-0.96	-1.44 – -0.48	
Other	-1.18	-4.73 – 2.36	
Not reported	-1.10	-2.19 – 0.02	

CI: Confidence Interval
NB: Comorbidity data were not recorded for all patients.
*Pre-existing health problems refers to any of the comorbidities, i.e., respiratory, cardiovascular, mental health and diabetes.
§No patients identifying as Black ethnicity were recorded in the data.

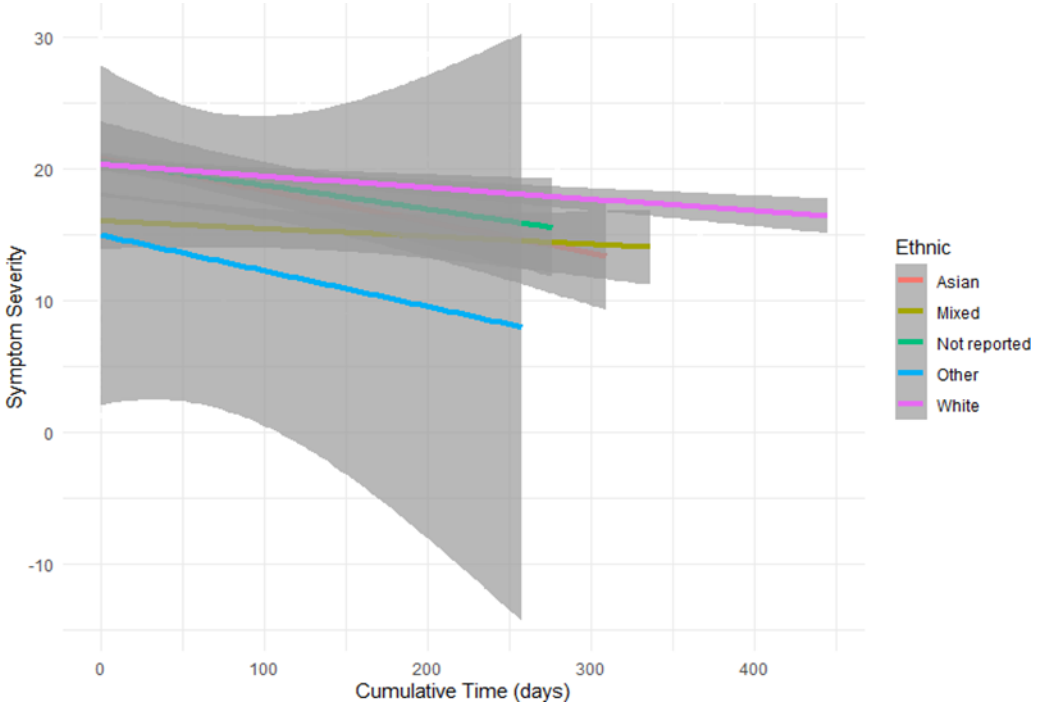
Figure 5 demonstrates that Symptom Severity improved for all age groups between 18 to 60+ years over time. Overall, there was no evidence of a difference in symptom trajectories across all the age groups (p=0.58, Table 7). However, the 40-49 age category appeared to show the least improvement in Symptom Severity over time, compared to observed improvements in all the other age groups.

Figure 5. Symptom Severity over Time by Age Category



In terms of ethnicity, no patients identifying as Black were recorded in the dataset. White and Asian patients (and those not reporting ethnicity) had the highest Symptom Severity scores at the first assessment (for instance, on average 4 points higher compared to Mixed ethnicity). This may suggest that some ethnic groups are more susceptible to worse symptoms, or a difference in referral patterns however, there was no evidence of different symptom trajectories over time (Figure 6) between ethnic groups and no statistically significant differences (p=0.99, Table 7). It is worth noting that the confidence intervals (Figure 6) were very wide, and it is therefore recommended that recording of data on ethnicity is improved upon in order to better identify whether needs of different groups are being equitably met.

Figure 6. Symptom Severity over Time by Ethnicity



Time since completion of the first PROM was dichotomised into ≤ 90 days and >90 days after the first assessment. The findings suggested that patients experienced faster improvement (steeper decline symptom scores on average) during the first 90 days from first assessment, compared to subsequent assessments, and this was statistically significant (p=0.022).

It is important to note that 90 days was an arbitrary cut-off, and that further work would be needed to quantify exactly when most improvement was seen. Furthermore, the slower improvement beyond 90 days may reflect a different population with more persistent problems, who take longer to discharge and therefore are more likely to provide longer term data, rather than indicating any lack of benefit of intervention beyond the first 90 days.

The dates when patients completed PROMs were not necessarily the same date as their clinical assessments. For example, patients in NHS Highland and NHS Lanarkshire are requested to complete PROMs following initial registration to the app but they may not receive a first clinical assessment for some time thereafter.

Non-active responders

The analysis of non-active responders revealed that 82% (N=569) of participants had only completed the C19-YRSm once in the study period (up February 2024). Statistically significant predictors of non-active responders included age, Symptom Severity and Overall Health (see Table 8). Non-active responders were more likely to be younger with poorer Overall Health and higher Symptom Severity scores.

Table 8. Predictors of non-active responders

Predictors	Odds Ratios	CI	p
(Intercept)	1.42	0.12 – 16.94	0.779
Sex [Male]	0.74	0.38 – 1.47	0.384
Age	0.97	0.94 – 1.00	**0.046**
Symptom Severity	1.15	1.04 – 1.27	**0.006**
Functional Disability	0.96	0.83 – 1.10	0.569
Overall Health	1.25	1.02 – 1.56	**0.041**
Other Symptoms	0.94	0.85 – 1.03	0.182
Infection Time	1.00	1.00 – 1.00	0.257
Observations	323		

CI: Confidence Interval.

The response rates from this NSS service evaluation could not be directly compared with those from NHS England, given NHS services in England had generally been using the ELAROS digital platform for longer, so had greater opportunity for individual patients to provide a second or third measurement during that period.

DISCUSSION

This baseline service evaluation has shown that patients with LC in Scotland have a substantial new onset of symptoms and functional disability following their acute COVID-19 infection. Morbidity associated with LC persists in some patients, even at 180 days (6 months) after referral to (and starting to be seen in) a specialist LC clinic.

The LC services have a greater proportion of middle-aged females. This sample also predominantly comprised of non-hospitalised patients (88%) with a high prevalence (38%) of co-morbidities, which is also consistent with characteristics of patients with LC reported in other studies.5,6 It is possible that individuals with co-morbidities might be more prone to developing LC requiring referral. However, it is also possible that people with co-morbidities are more frequent attenders with their GP, and therefore may be more likely to be referred for that reason.

The ELAROS platform in this service evaluation was used to complete a total of 1,877 PROMs (C19- YRSm and EQ5D) which is encouraging in terms of a novel concept of using an interactive digital system for patients to complete PROMs in their own time. This reduces the administrative burden within LC services which have collected and analysed PROMs manually. It is also reassuring that some patients completed multiple PROM assessments on the platform.

The cross-sectional EQ-5D-5L index value of 562 patients suggests the burden and disability in this cohort of LC patients were worse than in Diabetes Mellitus, Chronic Obstructive Pulmonary Disease (COPD), Heart Failure, and Multiple Sclerosis (Table 9).15,16 This is concerning evidence that LC is relatively more debilitating than many chronic health conditions. Nonetheless, it provides impetus for services to recognize LC as a new long-term condition and orient services to manage this as comprehensively as possible. It also calls for further research which helps to advance our understanding of this complex condition and tests new emerging treatments.

Table 9. Comparison of EQ-5D-5L Index Scores in LC and other chronic long-term conditions†

Condition	EQ-5D Index (SD)
Healthy population	0.92 (0.17)
Diabetes mellitus (type 2)	0.79 (0.22)
Heart failure	0.60 (0.25)
Multiple sclerosis	0.59 (0.29)
Long COVID (this service evaluation study)	0.40 (0.29)

† Janssen et al. *Eur J Health Econ* 2021; 22: 1467-75; Zhou et al. *Frontiers Public Health* 2021; 9: 675523

Small improvements in Symptom Severity, Functional Disability and Overall Health were observed at three months following the initial PROM assessment. However, they continued to experience significant symptom burden and disability compared to their pre-COVID-19 health status. These findings show that many patients require longer than 3 months under the care of LC service to achieve complete recovery. Continuing to monitor service data will help provide an insight into the approximate length of follow-up which may be required for patients.

Only 14% of our sample were able to maintain their role prior to their COVID-19 infection without changes to their working arrangements. Over two thirds (70%) were required to either: take sick leave, reduce their hours, change their role, retire, or lose/quit their job. These figures are similar to those found in NHS England LC services, with 21% maintaining their job while 62% changed their working arrangements (data not shown). This has an impact on productivity loss and uptake of state benefits, illustrating there is a clear need to create and implement effective occupational rehabilitation programmes within LC services.

Research examining multiple assessments undertaken in the same LC patients over time has revealed that LC can be a fluctuating condition.17 This means there is not necessarily a linear trend of improvement or deterioration in the symptom burden, functional disability, and overall health of patients. Hence, care needs to be taken in drawing any conclusions changes in PROM scores, particularly when over a short space of time. Again, more regular and repeated assessments over the longer-term are required to assess changes with more certainty. In this context, the Symptom Severity score of C19-YRSm appears to be a better indicator relative to the EQ-5D-5L index scores due to the greater degree of responsiveness as demonstrated by SRMs. The fluctuating nature of LC should also be considered when determining how

ongoing care of LC patients is going to be planned in future; patients could re-present to services even after discharge when they have a relapse of symptoms.

The EQ-5D-VAS allows the patient to say overall whether their health is improving or not. The finding that this correlates well with the C-19 YRS and not the EQ-5D-5L, it implies that the C-19 YRS may be better at indicating patients' own perceptions of outcomes from long COVID compared to the EQ-5D-5L. A reason behind this could be that the C-19 YRS is a more condition-specific measure while the EQ-5D-5L is a generic measure.

The analysis of non-active responses suggested that younger patients with poorer health (including those with a higher symptom burden) were less likely to complete the assessments (C19-YRSm) more than once. This suggests that the results here may under-estimate the symptom burden and relative impact on quality of life. If patients with the highest symptom burden were also to benefit most from intervention, then this would also under-estimate the improvement in symptoms experienced by patients through LC services.

We also compared the results from this evaluation with the NHS England evaluation of LC services in 2023 which collected similar data, albeit from a much larger cohort of patients and over a longer period. There was little to separate the two populations in terms of patient characteristics (Table 10). Nevertheless, there was a large difference in levels of pre-COVID comorbidities (NHS Scotland 38% vs NHS England 10%). This could be due to more incompleteness in the earlier NHS England dataset or real differences in the profile of patients between the two countries.

For the other comparisons, those minor differences that were present indicated that the average age of patients presenting to LC services in Scotland was slightly higher than English counterparts (52 vs 48 years, respectively). Furthermore, slightly higher numbers in Scotland had been admitted to hospital (12.5% vs 10%) and to ICU (5% vs 2%).

In terms of health outcomes measured by the PROMs, there were no or very few differences: Symptom Severity and Functional Disability were slightly lower by roughly 1 point (i.e. better HRQoL) for England with the only noticeable differences recorded for the EQ-5D-5L, which was lower (poorer HRQoL) for Scotland.

with the only noticeable differences recorded for the EQ-5D-5L, which was lower (poorer HRQoL) for Scotland.

Table 10. Comparison of PROMS (first assessment): NHS England with NHS Scotland

Country	Pre/Now	Symptom Severity	Functional Disability	Overall Health	Other Symptoms	EQ-5D-5L Index value	EQ-5D VAS
England	Pre COVID	4.1	1.1	7.5	-	-	-
Scotland	Pre COVID	4.3	1.2	6.4	-	-	-
England	First assessment	18.6	7.1	4.5	5.7	0.50	51
Scotland	First assessment	19.7	8.7	4.0	7.0	0.41	45

LIMITATIONS

There are several limitations to this baseline evaluation. Firstly, this sample includes only one source of data which is extracted from the digital platform (ELAROS). We do not have data from those completing PROMs using paper forms or using other digital platforms within LC services, nor from elsewhere in the healthcare system where clinical support may be provided to LC patients. For example, NHS Lothian use the Pogo Healthcare platform, incorporating a shorter list of symptoms than the C19-YRS. We would have liked to have incorporated some of their results and compared patient profiles with those included in this report to ensure the experience of patients in the Lothian region was represented in our findings. However, this information was not available in time to be included in the current report. Future work should allow for data collection from additional sources, allowing for potentially different case-mix.

Conclusions have been drawn from a small subgroup of participants. The majority of patients in this sample were being seen by two NHS Boards. The NHS services provided by these Boards, or the patients in their care, are therefore not representative of the wider population of people using NHS LC services in Scotland. This is largely because the digital platform has only very recently been rolled out to Boards and at different times, so is not fully integrated into all the different pathways. In addition, at the time of data analysis, five Health Boards were still in the process of implementing the system.

Patients who chose not to consent to sharing their pseudonymised data were also excluded, further reducing the sample size from each clinic. This limitation however does not influence the conclusions that in a subset of patients, LC symptom burden, functional limitation burden, and vocational problems, evolve into a long-term condition.

Data quality could be improved. For example, the recorded length of follow-up using the digital platform does not necessarily reflect total time in the service; some patients may have been registered onto the app and completed their PROMs long before they were seen by a health professional. Therefore, time could also be a predictor of improvement versus being seen by a LC service.

In addition, some Boards with dedicated LC services may have registered patients on the digital tool who did not have LC but were being reviewed by the service (e.g. as in Highland).

The proportion of participants with repeated PROMs data is low, dropping by more than 50% between first and second assessments. It is possible that incomplete records are more frequent in patients whose symptoms improved, leading them to stop monitoring their symptoms. On the other hand, it is also possible that those whose symptoms deteriorated were too fatigued to complete the PROMs. Even those with no change in symptoms may have lost hope of seeing any improvement. We are unable to take account of this potential informative missingness, and conclusions assume measurements are missing at random. Nonetheless, completeness rates were comparable to reported rates in the literature. Some studies using digital PROMs in other conditions have reported non-use rates to be as high as 72%.18,19,20 However given the advantages and the emphasis on digitalisation of NHS services and move to bring care as close as possible to patients' homes, the use of digital PROMs is an efficient way of collecting PROMs in future.

It should be noted that there is significant variation exists in how each LC service is run. This impacts on data collection, for example the frequency with which services conduct follow-up assessments of patients. Many participating services collect PROMs to support the initial assessment and triaging, but do not collect follow-up outcomes at routine intervals, despite functionality with the ability to set automated reminders being available in the ELAROS platform which is used in other services. Completion rates were also differentially influenced by LC services; initially one service made it mandatory to complete the assessment on the digital tool in order to access an appointment but this practice has since changed.

It had been hoped at the outset of this study that we could evaluate the benefit of additional resources on patient outcomes. However, it was agreed to try not to make use of the digital tool too burdensome for patient, who would likely be fatigued. We are aware of a further Chief Scientist Office-funded study being undertaken by the Universities of Glasgow and Stirling which is exploring and describing different models of long COVID care by Boards. In future, we hope to be able to triangulate the findings from this study with any further analyses of data from the digital tool to better compare different service models.

The potential for digital exclusion needs to be considered but we have not been able to analyse the trends in those individuals filling out PROMs using more traditional approaches. The ELAROS platform offers the functionality to support telephone

assessments and to upload paper-based assessments which could be used in future with patients who prefer not to or cannot use the mobile app.

Ethnic group was unrecorded for one third of patients, with no patients identifying as Black recorded in the dataset. Results suggested that some ethnic groups may have experienced more severe symptoms or differences in referral patterns, but there was no evidence of differences in symptom trajectories between ethnic groups over time. However, conclusions cannot be drawn on account of a third of patients not having complete data on ethnicity.

We were unable to compare different types of service provision, models of care, or different interventions, in relation to patient outcomes. Nor were we able to investigate the relative cost-effectiveness of different service models or interventions. Future work would need to capture additional information over a much longer period, and from more Health Boards if we are to have a more national picture.

Finally, we had not included a patient representative at the outset of planning this analysis. Future work should ensure we include patients with lived experience to help advise on the future design, collection and analysis of data.

RECOMMENDATIONS

Health Boards and the LC Network

- Recognise LC is a new-onset condition with a significant burden of symptoms, functional disability and decline of overall health in affected individuals. Even though there is a lack of a single uniform biomarker yet for the condition, the findings of this study support a significant healthcare burden, including in many previously healthy and fit individuals.
- Recognise that in many individuals LC is a chronic condition that fluctuates from day-to-day and requires long-term care with a similar strategy to other long-term conditions.
- There is a clear need for LC services to identify rehabilitation interventions which would also support individuals to return to work. LC has a significant impact on individual work productivity (sick leave) and ability to work (change in working arrangements, reduced working hours). It also impacts on employers and the state, for instance, through the increased the cost of disability allowances, and reduced tax revenue through less participation in the work force.
- The cost-effectiveness of using digital PROMs platforms to monitor patient symptom trajectories, provide information prior to clinical appointments, and potentially offer a platform for delivery of self-management tools should be evaluated.
- As in other areas of society, it is important that a transition to systems requiring access to internet-enabled devices does not widen health inequalities. This is consistent with wider societal needs to address the barriers of digital exclusion, to provide public-access devices, ensure affordable internet access is available, and provide adequate training for individuals to take-up the use of such technology.
- Continue to encourage the collection of PROMs within all LC services. With many people now living with LC for over two years, there is a need to capture longer-term outcomes from a wider and more representative range of sites. Learn from other areas what works to improve response rates. Also involve patient representatives from the beginning of plans for data collection and analysis.

- Continue to advocate for more research to understand the condition better and improve outcomes for patients will help us better understand and manage this complex condition.
- Given the short-term follow-up available within this evaluation, we recommend LC services are re-evaluated in between 6 to 12 months' time. In addition, given that services are likely to change how they are delivered, the current evaluation could form a baseline from which to compare different service models in relation to patient outcomes.
- Consider how future analyses of PROMs data could be triangulated with information around what we know about difference models of LC services. This could help advance understanding on how to provide care which is most effective for patients. For example, the Universities of Glasgow and Stirling are undertaking research into LC services available across the country as well as how these can be improved upon. Future analysis should also attempt to include comparable data from Health Boards not using ELAROS to obtain as complete a national picture as possible.
- Further work exploring how best to support people to complete PROM assessments may be required. The non-active responder analysis indicates this group is likely to be younger and with more severe symptoms; it is possible that 3 monthly completion is too frequent/burdensome for this cohort of patients so alternative mechanisms for monitoring their clinical condition may be needed. The value of monitoring outcomes would be both to patients to inform their longer-term care, as well as in helping to provide more complete and representative data to inform improvements in services.
- As with other services, recording of ethnic group permits better exploration of any differences in symptom trajectories and potential inequalities in referral pathways and access to care. Similarly, up-to-date postcode information allows reporting by deprivation score of the area in which they live.

Individuals with LC

- This report is based on people living with LC who have been referred to NHS LC services and assessed at least once in the service. However, it represents only a small proportion of those known to be experiencing symptoms of LC. Having a clinical diagnosis can be key to successful intervention and long-term management supported by health professionals, in addition to self-management. Individuals with persistent symptoms need to present to their general practitioner to seek specialist input.
- Completing PROMs on a regular basis will provide individuals with LC with an ongoing record of their condition, helping both themselves and health professionals to better understand disease trajectories and manage their condition.
- Individuals with LC should continue to work closely with healthcare professionals and healthcare providers to enhance collective understanding of the condition.

Where can I find the Lay Summary?

The Lay Summary of this report is available on the Long Covid Service website: NHS Scotland Service Evaluation of Long-COVID Services- A Lay Summary

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APPENDIX A: C19-YRSm PROM

Modified COVID-19 Yorkshire Rehabilitation Screening (C19-YRS) Self-report version

Patient name:

NHS number:

Date: Time:

The purpose of this questionnaire is to find out more about your current problems following COVID- 19 illness. Your responses will be recorded in your clinical notes. We will use this information to monitor your symptoms, offer treatments and assess response to treatment.

This questionnaire will take around 15 minutes. If there are any topics you do not want to talk about you can choose not to respond.

Do you consent for this information to be used for audit and research as well?

Yes ☐ No ☐

SYMPTOM SEVERITY

Please answer the questions below to the best of your knowledge.
'Now' refers to how you feel now/this week (last 7 days).
"Pre-COVID" refers to how you were feeling prior to contracting the illness. If you are unable to recall this, just state 'don't know'

Rate the severity of each problem on a scale of 0-3:
0 = None; no problem
1 = Mild problem; does not affect daily life
2 = Moderate problem; affects daily life to a certain extent
3 = Severe problem; affects all aspects of daily life; life-disturbing

Symptom		Now	Pre-COVID
1. Breathlessness	a) At rest	0 ☐ 1 ☐ 2 ☐ 3 ☐	0 ☐ 1 ☐ 2 ☐ 3 ☐
	b) Changing position e.g. from lying to sitting or sitting to lying	0 ☐ 1 ☐ 2 ☐ 3 ☐	0 ☐ 1 ☐ 2 ☐ 3 ☐
	c) On dressing yourself	0 ☐ 1 ☐ 2 ☐ 3 ☐	0 ☐ 1 ☐ 2 ☐ 3 ☐
	d) On walking up a flight of stairs	0 ☐ 1 ☐ 2 ☐ 3 ☐	0 ☐ 1 ☐ 2 ☐ 3 ☐
2. Cough/ throat sensitivity/ voice change	Cough/ throat sensitivity	0 ☐ 1 ☐ 2 ☐ 3 ☐	0 ☐ 1 ☐ 2 ☐ 3 ☐
	Change of voice	0 ☐ 1 ☐ 2 ☐ 3 ☐	0 ☐ 1 ☐ 2 ☐ 3 ☐
3. Fatigue (tiredness not improved by rest)	Fatigue levels in your usual activities	0 ☐ 1 ☐ 2 ☐ 3 ☐	0 ☐ 1 ☐ 2 ☐ 3 ☐

Symptom		Now	Pre-COVID
4. Smell/taste	Altered smell	0 ☐ 1 ☐ 2 ☐ 3 ☐	0 ☐ 1 ☐ 2 ☐ 3 ☐
	Altered taste	0 ☐ 1 ☐ 2 ☐ 3 ☐	0 ☐ 1 ☐ 2 ☐ 3 ☐
5. Pain/discomfort	Chest pain	0 ☐ 1 ☐ 2 ☐ 3 ☐	0 ☐ 1 ☐ 2 ☐ 3 ☐
	Joint pain	0 ☐ 1 ☐ 2 ☐ 3 ☐	0 ☐ 1 ☐ 2 ☐ 3 ☐
	Muscle pain	0 ☐ 1 ☐ 2 ☐ 3 ☐	0 ☐ 1 ☐ 2 ☐ 3 ☐
	Headache	0 ☐ 1 ☐ 2 ☐ 3 ☐	0 ☐ 1 ☐ 2 ☐ 3 ☐
	Abdominal pain	0 ☐ 1 ☐ 2 ☐ 3 ☐	0 ☐ 1 ☐ 2 ☐ 3 ☐
6. Cognition	Problems with concentration	0 ☐ 1 ☐ 2 ☐ 3 ☐	0 ☐ 1 ☐ 2 ☐ 3 ☐
	Problems with memory	0 ☐ 1 ☐ 2 ☐ 3 ☐	0 ☐ 1 ☐ 2 ☐ 3 ☐
	Problems with planning	0 ☐ 1 ☐ 2 ☐ 3 ☐	0 ☐ 1 ☐ 2 ☐ 3 ☐
7. Palpitations/ dizziness	Palpitations in certain positions, activity or at rest	0 ☐ 1 ☐ 2 ☐ 3 ☐	0 ☐ 1 ☐ 2 ☐ 3 ☐
	Dizziness in certain positions, activity or at rest	0 ☐ 1 ☐ 2 ☐ 3 ☐	0 ☐ 1 ☐ 2 ☐ 3 ☐
8. Post-exertional malaise (worsening of symptoms)	Crashing or relapse hours or days after physical, cognitive or emotional exertion	0 ☐ 1 ☐ 2 ☐ 3 ☐	0 ☐ 1 ☐ 2 ☐ 3 ☐
9. Anxiety/ mood	Feeling anxious	0 ☐ 1 ☐ 2 ☐ 3 ☐	0 ☐ 1 ☐ 2 ☐ 3 ☐
	Feeling depressed	0 ☐ 1 ☐ 2 ☐ 3 ☐	0 ☐ 1 ☐ 2 ☐ 3 ☐
	Having unwanted memories of your illness or time in hospital	0 ☐ 1 ☐ 2 ☐ 3 ☐	0 ☐ 1 ☐ 2 ☐ 3 ☐
	Having unpleasant dreams about your illness or time in hospital	0 ☐ 1 ☐ 2 ☐ 3 ☐	0 ☐ 1 ☐ 2 ☐ 3 ☐
	Trying to avoid thoughts or feelings about your illness or time in hospital	0 ☐ 1 ☐ 2 ☐ 3 ☐	0 ☐ 1 ☐ 2 ☐ 3 ☐
10. Sleep	Sleep problems, such as difficulty falling asleep, staying asleep or oversleeping	0 ☐ 1 ☐ 2 ☐ 3 ☐	0 ☐ 1 ☐ 2 ☐ 3 ☐

FUNCTIONAL ABILITY

Symptom		Now	Pre-COVID
11. Communication	Difficulty with communication/word finding difficulty/understanding others	0 ☐ 1 ☐ 2 ☐ 3 ☐	0 ☐ 1 ☐ 2 ☐ 3 ☐
12. Walking or moving around	Difficulties with walking or moving around	0 ☐ 1 ☐ 2 ☐ 3 ☐	0 ☐ 1 ☐ 2 ☐ 3 ☐
13. Personal care	Difficulties with personal tasks such as using the toilet or getting washed and dressed	0 ☐ 1 ☐ 2 ☐ 3 ☐	0 ☐ 1 ☐ 2 ☐ 3 ☐
14. Other activities of Daily Living	Difficulty doing wider activities, such as household work, leisure/sporting activities, paid/unpaid work, study or shopping	0 ☐ 1 ☐ 2 ☐ 3 ☐	0 ☐ 1 ☐ 2 ☐ 3 ☐
15. Social role	Problems with socialising/interacting with friends* or caring for dependants *related to your illness and not due to social distancing/lockdown measures	0 ☐ 1 ☐ 2 ☐ 3 ☐	0 ☐ 1 ☐ 2 ☐ 3 ☐

OTHER SYMPTOMS

Please select any of the following symptoms you have experienced since your illness in the last 7 days. Please also select any previous problems that have worsened for you following your illness.

- ☐ Fever
- ☐ Skin rash/ discolouration of skin
- ☐ New allergy such as medication, food etc
- ☐ Hair loss
- ☐ Skin sensation (numbness/tingling/itching/nerve pain)
- ☐ Dry eyes/ redness of eyes
- ☐ Swelling of feet/ swelling of hands
- ☐ Easy bruising/ bleeding
- ☐ Visual changes
- ☐ Difficulty swallowing solids
- ☐ Difficulty swallowing liquids
- ☐ Balance problems or falls
- ☐ Weakness or movement problems or coordination problems in limbs
- ☐ Tinnitus
- ☐ Nausea
- ☐ Dry mouth/mouth ulcers
- ☐ Acid Reflux/heartburn
- ☐ Change in appetite
- ☐ Unintentional weight loss
- ☐ Unintentional weight gain
- ☐ Bladder frequency, urgency or incontinence
- ☐ Constipation, diarrhoea or bowel incontinence
- ☐ Change in menstrual cycles or flow
- ☐ Waking up at night gasping for air (also called sleep apnea)
- ☐ Thoughts about harming yourself

Other symptoms – free text

OVERALL HEALTH

How good or bad is your health overall in the last 7 days?

For this question, a score of 10 means the BEST health you can imagine. 0 means the WORST health you can imagine.

Now:

WORST HEALTH 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 ☐ BEST HEALTH

Pre-Covid:

WORST HEALTH 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 ☐ BEST HEALTH

EMPLOYMENT

Occupation:

Has your COVID-19 illness affected your work??

- ☐ No change
- ☐ On reduced working hours
- ☐ On sickness leave
- ☐ Changes made to role/ working arrangements (such as working from home or lighter duties)
- ☐ Had to retire/ change job
- ☐ Lost job

Any other comments/concerns:

PARTNER/FAMILY/CARER PERSPECTIVE

This is space for your partner, family or carer to add anything from their perspective: