

A cross-sectional analysis from the PAC-19QoLReg on the association between Quality of Life (QoL) of long COVID-19 patients and their disease duration

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Abstract

Background: The COVID-19 pandemic has been recognized for its long-term detrimental effects on the human population. The aim of this study was to report on the quality of life (QoL) from the interim analysis of COVID-19 positive patients registry data (PAC-19QoLReg) at baseline.

Method: Self-declared patients who received COVID-19 positive diagnosis and/or had exhibited symptoms of lagged effects from post-COVID-19 for a duration of at least 28 days were recruited into the PAC-19QoLReg in December 2020 via social media, broadcasting platforms community forums and by word-of-mouth.

Results: At primary recruitment, a total of 107 participants were recruited into the study. However, this interim data reports on N=74 long COVID-19 patients who have completed their baseline PAC-19QoL; Survey 1. The generalized linear model (GLM) Poisson regression was applied in this study to examine the association between exposure duration to COVID-19 and PAC-19QoL scores. The finalized model was adjusted for truncation time and age at recruitment. Truncation time was considered for its contribution in the delayed effects to complete the questionnaire upon recruitment, and such postponement varied among participants. The findings demonstrate that all participants were likely to recover in their QoL scores with increasing time since being diagnosed with COVID-19. The model underwent an elective statistical adjustment with the UK-only participants, and with truncation time at 0-14 and beyond 14 days. Participants who took >14 days to complete the survey were likely to recover in QoL scores than ≤14 days.

Conclusion: Findings from this study suggests a disproportional impact on patients by gender, age, and study country was observed, emphasizing that an awareness of patient-specific factors can assist clinicians in identifying those who may be at risk for diminished QoL as they progress. Furthermore, psychological adaptation to disease symptoms upon COVID-19 diagnosis was observed among the participants

Trial registration: ClinicalTrials.gov Identifier NCT04586413 (14/10/2020)

Background

The COVID-19 pandemic has been recognized by the scientific, medical, economic, and political committees for its long-term detrimental effects on the human population.

Ongoing mutation of the COVID-19 virus continues to create impacts on rituals and routines that have been shown to lead to an impairment in the Quality of Life (QoL).¹⁻² Empirical data suggests that in August 2021, the estimated number of COVID-19 positive cases had exceeded 208 million globally, with 4.3 million reported COVID-19 deaths. In the United Kingdom, 10.9 million positive diagnoses have been recorded, with 146,627 deaths from the disease at the time of writing,³ indicating that the diminishing incidence of COVID-19 remains speculative.⁴⁻⁵

Recent scientific literature has suggested that post-COVID-19 patients have the ability to resume normal functioning, however, this is on the condition that they are not experiencing any previously diagnosed underlying morbidity.⁶ In contrast, a recent report suggests that recovered post-COVID-19 patients are exhibiting prolonged aftermath symptoms of the life-threatening respiratory disease.⁷ In clinical medicine, this state of prolonged symptoms following SARS-CoV-2 viral infection has been recognised as a discrete post-acute illness known as long COVID-19⁸, defined as ‘a collection of symptoms that develop during or following a confirmed or suspected case of COVID-19, and which continue for at least 28 days.⁷

The excess disease burden for long COVID-19 patients results in respiratory conditions, diseases of the nervous system, mental health burden, metabolic disorders, poor general wellbeing, cardiovascular conditions, gastrointestinal system conditions, skin disorders, urinary tract infections, and arthritis Al-Aly, et al.⁹. Many long COVID-19 patients have reported a combination of these collections of sequelae, thus highlighting a significant issue with the quality of life of affected long COVID-19 patients.¹⁰ Long COVID-19 has, thus, been suggested to be a collection of sequelae instead.

Although the understanding of long COVID-19 is still evolving⁷, the level of uncertainty regarding long-term health and well-being effects from long COVID-19 remains a public health priority. In recognition of the complicated nature of long COVID-19, the WHO has developed the following clinical case definition of long COVID-19:

"Post COVID-19 condition occurs in individuals with a history of probable or confirmed SARS CoV-2 infection, usually 3 months from the onset of COVID-19 with symptoms and that last for at least 2 months and cannot be explained by an alternative diagnosis. Common symptoms include fatigue, shortness of breath, cognitive dysfunction but also others and generally have an impact on everyday functioning. Symptoms may be new-onset following initial recovery from an acute COVID-19 episode or persist from the initial illness. Symptoms may also fluctuate or relapse over time."

While the WHO definition provides an efficient clinical diagnosis of the disease, observational cohort clinical studies or patient registries may be used to generate real-world evidence on disease progression and also help generate hypotheses on the benefits of available treatments in the real world.^{11 - 12} Recently, attention has been drawn to ensuring Neutrality¹³ when observing subjects in clinical studies. This is particularly applicable to the use of disease-specific tools, especially for measuring the quality of life in specific disease conditions.¹⁴ For this reason, a disease-specific tool (PAC-19QoL) measuring the impact of long COVID-19 on quality of life was developed and validated.¹⁵ This disease-specific tool adhered to the principles undergirding the Neutrality Theory¹³, and used the Jandhyala Method^{16 - 17} to generate a ‘best’ Neutral list of quality of life indicators that long COVID-19 patients suggest should be included in a long COVID-19 disease-specific quality of life tool. In order to implement the PAC-19QoL and begin the process of observing long COVID-19 sufferers’ QoL, a dedicated patient registry, the PAC-19QoL (ClinicalTrials.gov Identifier NCT04586413 (14/10/2020)) was developed and implemented in late 2020

with the primary objective of achieving a follow-up of 100 subjects over a period of 12 months. The overarching aim of this project is to conduct and report findings from the interim analysis of data from the long COVID-19 patient registry (PAC-19QoLReg). This analysis details the QoL scores of long COVID-19 patients with increasing time from diagnosis.

Methods

Cohort description

Ongoing recruitment of long COVID-19 patients into the PAC-19QoLReg commenced in December 2020 during initial deployment of the PAC-19QoL instrument. The PAC-19QoLReg is a patient registry dedicated to observing quality of life Post-Acute (long) COVID-19 patient using the PAC-19QoL, currently the only disease-specific long COVID-19 quality of life instrument.¹⁸ Participants were recruited from the validation study and adverts on social media, media broadcasting platforms, community forums and by word-of-mouth. A total of 107 participants have been recruited into the PAC-19QoLReg. All participants met the inclusion criterion of experiencing long COVID-19, at the time of completing their first survey, following a diagnostic or antibody test confirmation for SARS-COV-2 or a clinically suspected case of COVID-19. In addition, written informed consent was obtained from all participants during enrolment and all methods were performed in accordance with the relevant guidelines and regulations.

Statistical analyses

This analysis covered the baseline QoL measurements of COVID-19 positive patients, from the PAC-19QoLReg, who had exhibited COVID-19 symptoms for at least 28 days. Recruitment age was derived from the reported date of birth to the date of recruitment (Figure S1 & Table S1). Exposure time and truncation time were measured in days (Figures S3 & S4). For each participant, QoL scores were derived from a set of 44-questions that were to be completed each month over a 12-month period (Survey 1 to 12) (Figures 1, 2 & S5). Questions were scored on a Likert scale and their responses were summed at the end of each questionnaire. The data underwent a GLM Poisson regression analysis whereby the response variable was QoL scores, and potential predictor variables were selected using a forward-selection procedure (Table S4.1). The most preferred model was selected using the likelihood ratio test and with inference from Aikake Information Criteria (AIC). The finalized model contained the exposure time, truncation time and age in quartiles as predictor variables. For model selection and the preference for age in quartiles, refer to Table S4.1. All outliers were identified and excluded with the application of Cook's distance at $4/N$; *whereby N is the sample size*. After the exclusion of outliers, the elective analysis was performed with a truncation time within and beyond 14 days were performed; $N_{\text{all}} = 63$ and $N_{\text{UK}} = 53$ shown in Figure 3 (Tables S4.6.1-S4.6.4 for estimates output). Under appropriate statistical measures, the age quartiles in the UK-only finalized model was conditioned to have a valid baseline hazard and obtain non-misleading rate ratios; 22.0 - 38.5 Q1 was swapped with 38.6 - 45.0 Q2 category. All statistical analyses were performed using the anonymised dataset with R-software version 4.1.0.¹⁹

Missing values and Date inputs

Data collection was designed to reduce the possibility of missing values. In the selected variables of interest, there were no missing values. However, there were input errors in dates. For example, participants had the same dates for recruitment, diagnosis and completion of the survey. These participants had also experienced long COVID-19 symptoms and suffered from COVID-19 in the past, $N=2$. For these participants, we performed a bootstrap by replacing their exposure time with those from participants with similar demographics, *e.g.*, residential country and gender.

Results

Description of Study Participants

While a total of 107 patients were recruited into this study, this interim analysis reports the data analysis of long COVID-19 patients who had completed their baseline PAC-19QoL survey, $N=74$. For this interim report, the analysis represents the latest updates on 1st Dec 2021. After the exclusion of participants who did not meet the requirements of long COVID-19 symptoms, the descriptive analysis of their PAC-19QoL analysis was calculated (Table 1, Tables S1 – S3.2; Figures S1 - S5).

The health and demographic modules of the participants is presented in Table 1, $N = 74$. For information on the distribution of the participants by country and by age in quartiles, refer to Tables S1 – S3.2. Body Mass Index (BMI) was achieved by applying the formula: $\text{weight (kg)} / \text{height(m}^2\text{)}$ (Figure S2). Median age at recruitment was 45.2 ± 10.3 (F) and 43.8 ± 10.8 (M) (Figure S1.1 & S1.2).

Table 1

Demographic characteristics of participants experiencing COVID-19 symptoms for at least 28 days.

	All Countries (N=74)	UK-only (N=59)
Females (%)	87.8	88.1
Recruited age (median \pm sd)	45.2 \pm 10.4	47.5 \pm 9.9
Truncation time in days (median \pm sd)	1 \pm 24.3	1 \pm 33.4
Exposure time since diagnosis, days ^S (median \pm sd)	197.0 \pm 113.7	169.0 \pm 117.4
Body Mass Index	25.4 \pm 9.4	25.5 \pm 8.9
<u>Ethnicity_(%).</u>		
White	90.5	94.9
Mixed	1.4	1.7
Asian	2.7	1.7
Black	-	-
Other	5.4	1.7
<u>Smoking Status (%)</u> .		
Never	68.9	67.8
Former	28.4	32.2
Current	2.7	1.7
<u>Health Status (%)</u> .		
Recovered from COVID-19	23.0	20.7
Hospitalization	16.2	15.5
ICU ^o	41.7	44.4
Received major surgeries	21.6	20.7
<u>Morbidity_(N)</u> .		
Cancer	1	0
Cystic fibrosis	1	1
Stroke	0	0
High cholesterol	6	4
High blood pressure	9	5

Respiratory (COPD, Asthma)	24	19
Diabetes Type I & II	3	3
Other medical conditions	33	25
<u>Well-being_(%).</u>		
Post-COVID-19 mobility	75.7	78.0
Help with grocery shoppingnot required	74.3	72.9
Difficulty sleeping	71.6	67.8

COPD – chronic obstructive pulmonary disease

Participants resided in the United Kingdom (UK), United States, Columbia, Canada, Ireland, Morocco and Belgium (Table 1). Standard deviation was abbreviated as *sd*. *ICU^o* percentage and was derived from patients who were hospitalized. ^SExposure time was conditional for participants with < 28 days exposure, *N* = 2. The summation of numbers in each category may exceed or be below 1.0 or 100% due to rounding (Table 1).

The COVID-19 diagnosis of 87% of participants was confirmed through testing or clinical diagnosis. The remaining proportion was self-diagnosed without access to professional medical advice. Among participants, 58.7% declared that they had suffered from COVID-19 in the past, and 39.2 % were under full-time employment.

Table 2

Correlation between PAC-19QoL scores at baseline and exposure to long COVID-19 by age group.

Group	n	Mean	Median	IQR	Correlation coefficient	p-value
< 30 years	11	145	140	132.5,151	0.279	0.118
30-55 years	46	137.76	131.5	125.25,142	0.052	
> 55 years	17	127.76	131	117,137	0.159	
Control	16	78.75	80	64.25,97.5		
Validation group	15	136.33	139	124,149		<0.001*
Interim report set	74	136.54	132.5	123.5,141.75		<0.001*

Control group (n=15), Validation group (n=15) and Interim report set (n=74).

* *p-value < 0.05 is considered statistically significant*

Participant recruitment and retention

Findings from this report suggest that the recruitment rate was low, and attrition remained high with a large proportion dropping out after the first survey (Figure 1). A similar trend was observed after the second survey, in addition to deceleration on the attrition rate.

Statistical Analysis

Six participants completed twelve months in the study, and the twelve accompanying surveys. While this represents only 20% of the sampled population, the probability of participant retention was calculated, using the above data points as a reference (Figure 2). A retention rate of 100% was observed after completion of the send survey.

Model selection and truncation time

During the model selection, truncation time was introduced as a continuous variable and in categorical format: 0 days, 1-14 days; beyond 14 days (Table S4.1). Truncation time refers to the duration to complete the survey upon recruitment. In the finalized model, truncation time was categorized as within and beyond 14 days.

Discussion

Patient and Public Involvement

The PAC-19QoL instrument was developed with a group of long COVID-19 patients drawn from local, national, and international patient groups. It was a consensus on their desires on outcomes important for measuring their quality of life accurately that was used when selecting the final set of indicators included in the instrument. Their involvement has therefore been the foundation of the PAC-19QoL. Participants for this first phase and the patient registry were recruited through an advertisement of the study via social media platforms, such as Twitter, Facebook and LinkedIn, and contacts with relevant Facebook groups (such as groups for older adults in the UK, *e.g.*, U3A and groups for post-hospitalisation COVID-19 patients), and the Medialis Ltd website (www.medialis.co.uk). Participants were informed that at regular periods throughout the study data analysis and report production would occur, which may take the form of publicly accessible blog posts on the Medialis Ltd website. They were encouraged to continue informal dialogue with researchers on an *ad hoc* basis. The results of this study and further analyses of the PAC-19QoLReg will be submitted for publication in high impact factor peer-reviewed journals and communicated through conference presentations and other social medial channels.

PAC-19QoL validation vs healthy volunteer findings

Validation of any new instrument is of understandable interest and is considered an important threshold for its utility. To the best of the authors' knowledge, the PAC-19QoL remains the only disease-specific QoL instrument for long COVID-19 QoL. Importantly, research in QoL has confirmed the need for Neutrality in

indicator selection to ensure higher levels of accuracy in the measurement of this type of highly subjective construct. Generic instruments are not expected to respect the discipline required to limit observation to just the indicators relevant to a disease QoL and therefore cannot be reliably used to validate against. In developing a new long COVID-19 disease-specific QoL instrument, in the absence of a gold standard comparator, it was consequently decided to assess whether the instrument was able to reliably differentiate between individuals based on whether they had a long COVID-19 or not. The initial validation was carried out with 16 long COVID-19 patients and 15 healthy volunteers (Table 2).

Patient Registry Recruitment: Attrition Rates and Study Survey Completion

Rates of attrition are an important consideration in epidemiological studies.²⁰ The rate and timing have implications for the expected completion of the study and may infer fresh considerations for the execution of the study.²¹ Given the well-documented difficulties in long COVID-19 sufferers associated with brain fog, concentration and malaise after mental exertion, the prospect of completing even a relatively short survey of 44 questions may have prevented further participation. Interestingly, the retention rate observed within the initial 12 months of the study suggest that once a participant has completed the second survey, the probability of that participant following through with the remaining 10 surveys increases dramatically and remains stable for the duration of the remaining months (Fig. 2). However, a slight dip during month twelve was observed. This is likely attributed to holiday-malaise during the December festive period.

Patient registries of this nature rely exclusively on the patient's motivation to participate which may be driven by the perceived value of the research itself. As there are currently no associated services or interventions being evaluated on the PAC-19QoLReg such as long COVID-19 clinics, this may have impacted the perceived value of participation. Though scientific knowledge on disease progression and its impact on quality of life is of clear value in its own right, the inclusion of these relevant treatments and services would conceivably increase the perceived value of PAC-19QoLReg to both the clinicians running the service and the patients alike as well as raising awareness about the research and encouraging both participation and retention. At present, there is the expectation that the target 100 patients each completing 12 months would require at least 4,000 participants to compensate for the low retention probability and to continue subsequent surveys after the completion of the first survey. An improvement in both rates of recruitment and attrition must be prioritised to ensure a prompt delivery. Given the relatively small sample size required to complete this analysis, even modest improvements in the current recruitment or retention rates will have a significant in shortening the time to availability of the preliminary analysis.

Duration of Exposure, Truncation Time and QoL scores

The overarching aim of this study was to conduct and report on the interim analysis of data in the PAC-19QoLReg patient registry. Alongside the emergence of long COVID-19, were understandable concerns as to the long-term disease profile and rates of resolution, remission and relapse amongst those reporting

symptoms and signs of COVID-19 after 4 weeks.²² The exposure time was obtained from the date of recruitment and the date of the COVID-19 diagnostic test. The conditional probability of the study only permits patients who had received a COVID-19 positive diagnosis and exhibited health symptoms from COVID-19 infection for at least 28 days to participate in the study. Another time entity was also considered during the statistical analysis, truncation time. The truncation time was deduced from the date of recruitment to the date of survey completion (Table 1). Though 48.6% of the participants completed their survey on the date of recruitment, the remaining participants had various postponements in completing and submitting the survey. This postponement has the potential to cause misleading estimates during regression analysis.

One of the intriguing findings is that with increasing age quartiles the QoL scores decrease; a lower QoL score indicates a better Quality of Life. All age quartiles present a similar trend towards a recovery in QoL scores, while UK-only youngest age quartile at within-14 days truncation time demonstrates an increment in 12% QoL scores with statistical significance; 22.0–38.5 (Fig. 3 & Table S4.6.3). This is contradictory to the observed trend phenomenon in the analysis of all countries (Figure S8). While UK-only regression analysis would separate itself from statistical confounder errors deriving from country effects, the trend from UK-only > 14 days truncation time suggests that it is likely to be a psychological adaptation from prolonged effects of COVID-19 disease-related symptoms (Tables S4.6.1- S4.6.4). This adaptation may be happening among all post-COVID-19 and recovering patients in the world.²³ This phenomenon will be discussed in further detail in the subsequent sections.

Assessment of participant QoL reporting

Duration of exposure to COVID-19 in this long COVID-19 cohort showed an association with PAC-19QoL scores and the regression model demonstrated the importance of truncation time and the presence of age interactive effects; presented in quartiles with significance-level p -values < 0.05. Despite their QoL being significantly lower than COVID-19 negative controls¹⁸, there was an indication that QoL increases the longer a patient is living with the disease. While reports of long COVID-19 sufferers returning to health are available, concerns remain on whether this cohort may have simply adjusted to the lower QoL and, thus, perceived an improvement in their QoL. It is well established that dispositional optimism plays a role in both physical and mental wellbeing.^{24 - 25} This is defined as a measure of life engagement and generalised positive outcome expectancies for the future. A partial explanation of this is provided by the patient's engagement in a more adaptive coping strategy in the face of an uncontrollable stressor, such as COVID-19.²⁶ Since this involves interaction between the patient and his/her environment, it is reasonable to expect variation in the predisposition among people to cope in different ways.²⁷

Coping strategies and their impact on long COVID-19

Following the definition provided above, coping has been classified into three broad domains: cognitive, behavioural and emotional.^{28 - 29} Given that inherent changes in the ways people cope as they age exist, it has been postulated that during the ageing process individuals shift from problem-focused coping to emotion-focused coping.³⁰⁻³²

A wealth of knowledge has shown that younger age groups are more vulnerable to stress, depression, and anxiety symptoms.³³ While the general trend showed an improvement in QoL scores across the study population overall, the highest incidence of low QoL scores were recorded at baseline for the 22-38.5 age group. A recent study by Varma et al³³ examined the impact that the COVID-19 pandemic had on psychological stress globally. Their work highlighted that over 70% of the study population had greater than moderate levels of stress and that 59% of the cohort met the criteria for clinically significant anxiety.³³ In addition, 39% reported moderate depressive symptoms.³³

Interestingly, a number of studies have identified that age strengthens the ability to distance oneself from stressful situations.²⁸ As result, older participants report enhanced QoL both at baseline and throughout the progression of the study. The findings echo the results obtained in a study by Lim et al.³⁴ Their study on the interplay between anxiety, protective behaviours and resilience among the elderly found that greater resilience predicted lower anxiety among older adults.³⁴ Similarly, these findings provide support for the hypothesized beneficial role of coping flexibility in relieving heightened anxiety and depression, particularly when confronted by the vicissitudes which emerged during the COVID-19 pandemic.

Projected completion

The project has a goal of achieving 100 sets of 12-month surveys. From the probabilities of participation after the completion of Survey 1, it is estimated that at least 4,000 participants have to participate to achieve 100 sets of Survey 1–12 (Fig. 2).

Limitations Of The Study

Gender Differences and long COVID-19 Sequelae

This study design had limitations in achieving a balanced gender ratio for a comparative analysis between the two genders. Participants were mostly recruited through digital social media and forums which would have led to an algorithmic bias on the platform in calling for participants. Though it is unclear how the disease progression of long COVID-19 affects males and females³⁵ evidence from Pradhan and Olsson³⁶ and Rozenberg, et al.³⁷ suggest that males have a higher likelihood for mortality from COVID-19. There is an emerging body of evidence suggesting that females are more prone to the burden of long COVID-19 than males and in specific to ages between 40 and 60 years old.³⁸ Table 1 further suggests that the participants are health-conscious individuals with a right-tailed BMI density distribution with a median at 25.4 ± 9.4 and containing $< 3\%$ current smokers (Table 1 and Figure S2). Furthermore, it would also appear that cumulatively, females are more likely to participate in COVID-19 studies³⁸, in line with the existing opinion that females are more likely to participate in research studies in general (Table 2).^{39 – 40} This is likely due to the fact that most of COVID-19 social media support groups have been initiated by women.⁴¹

Small sample size and implications thereof

Despite the small sample size, this report has demonstrated that with the appropriate statistical approach and data conditioning, it is plausible to obtain meaningful interpretations and association findings on QoL and long COVID-19 exposure time. The analysis has demonstrated that long COVID-19 patients are recovering to a better QoL score and psychological adaptation to disease symptoms may have a substantial interference on QoL scores at the time of survey completion. It must be noted that the small sample size limits the degree to which the results can be reasonably generalised to the overall population of long COVID-19 sufferers. Upon the exclusion of the outliers using Cook's distance approach, the regression model suffers from a loss in statistical power whereby the significance of each category with increasing exposure time becomes challenging to depict (Figures S9 & S10). High initial attrition rates are a clear limitation to the population size available for this analysis and have been highlighted as an area for improvement or at least focus (Tables S11 – S12). The primary analysis explored the possibility of an association between exposure to long COVID-19 at baseline, however, true progression of the disease on sufferers' QoL can only be confirmed prospectively, and then only, with greater numbers. No assessment of interventions is planned, at present.

Conclusion

To the best of our knowledge, this is the first study to assess the impact of long COVID-19 on QoL across multiple geographical locations. A disproportional impact on patients by gender, age, and study country was observed, emphasizing that an awareness of patient-specific factors can assist clinicians in identifying those who may be at risk for diminished QoL as they progress. Further research using the PAC-19QoL in clinical studies is ongoing and actively supported with the PAC-19QoLReg. It is hoped that this patient registry will continue to generate valuable scientific knowledge on the progression of long COVID-19 QoL.

Abbreviations

AI: Awareness Index

CI: Consensus Index

COPD: Chronic Obstructive Pulmonary Disease

COVID-19: SARS-CoV-2 2019

PAC-19QoL: post-Acute (long) COVID-19 Quality of Life

PAC-19QoLReg: post-Acute (long) COVID-19 Quality of Life Patient Registry

QoL: Quality of Life

Sd: Standard deviation

Declarations

Competing Interests Declaration

The author is a visiting senior lecturer at the Centre for Pharmaceutical Medicine Research at King's College London responsible for research into real-world evidence approaches.

The author is also the Founder and CEO of Medialis Ltd, a medical affairs consultancy and contract research organization involved in the design and delivery of real-world evidence including the patient-reported outcomes and patient registries.

Availability of data and material

Data from this study will be made available upon reasonable request to the author - Ravi Jandhyala.

Author Contributions

RJ conducted the study and prepared, authored and approved the manuscript. The author also designed and implemented the patient registry. The author affirms that the manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; any discrepancies from the study as planned (and, if relevant, registered) have been explained. YL planned and conducted the GLM Poisson regression analysis and edited the manuscript.

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Ethical Approval

The study was approved by the South West – Central Bristol Research Ethics Committee (IRAS 288729 Bristol SW REC). All research was performed in accordance with relevant guidelines/regulations and according to the WMA Declaration of Helsinki (2013) ⁴².

Consent to Participate

Written informed consent was obtained from all participants during enrolment and they were provided the complete study details.

Consent for Publication

Not Applicable.

Transparency Declaration

Medialis continues to run the PAC-19QoLReg patient registry in association with the Centre for Pharmaceutical Medicine Research, Institute of Pharmaceutical Science, Faculty

of Life Science & Medicine, King's College London, as part of its Corporate Social Responsibility Project.

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Figures

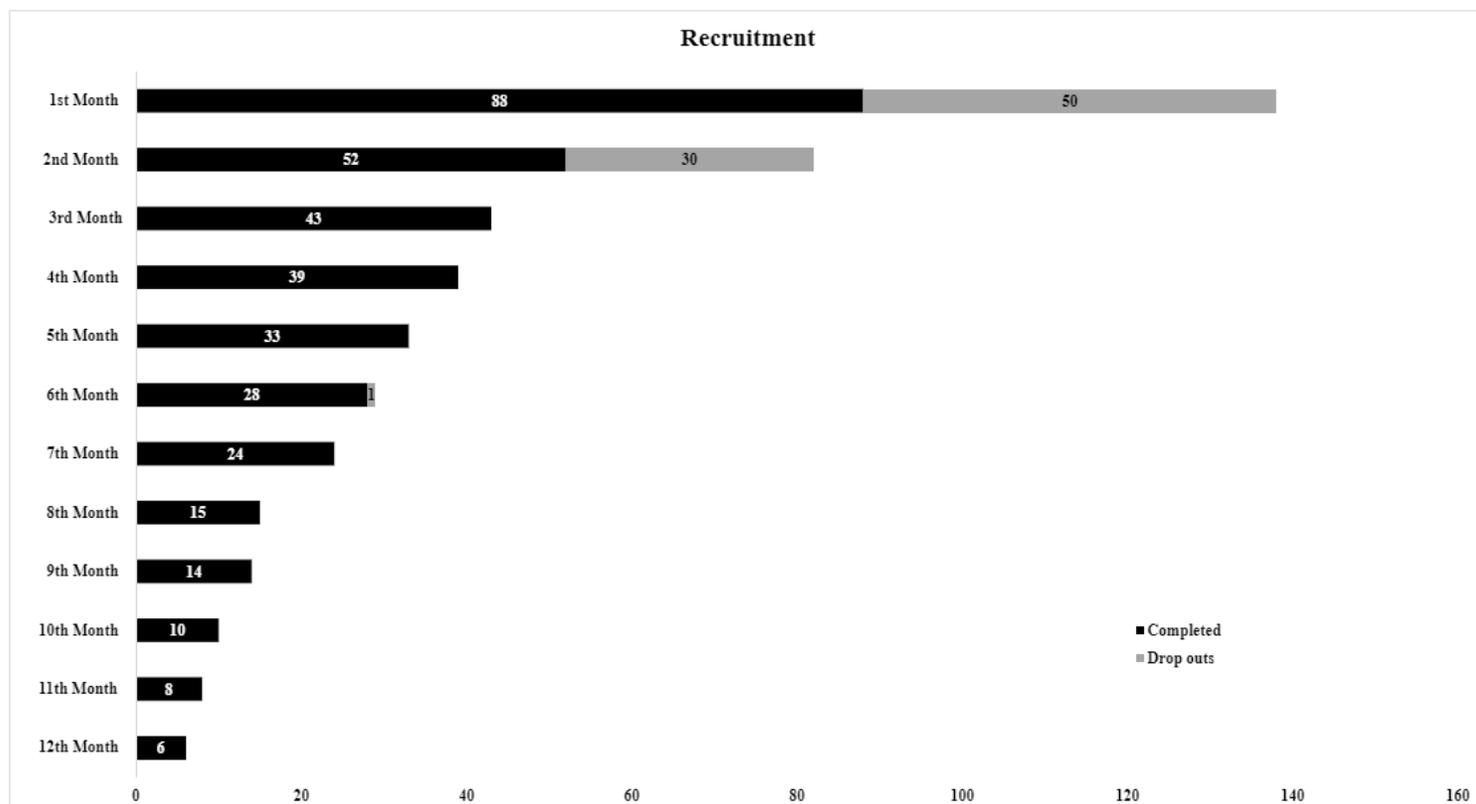


Figure 1

Participant retention over the first 12 months of implementing the PAC-19QoLReg.

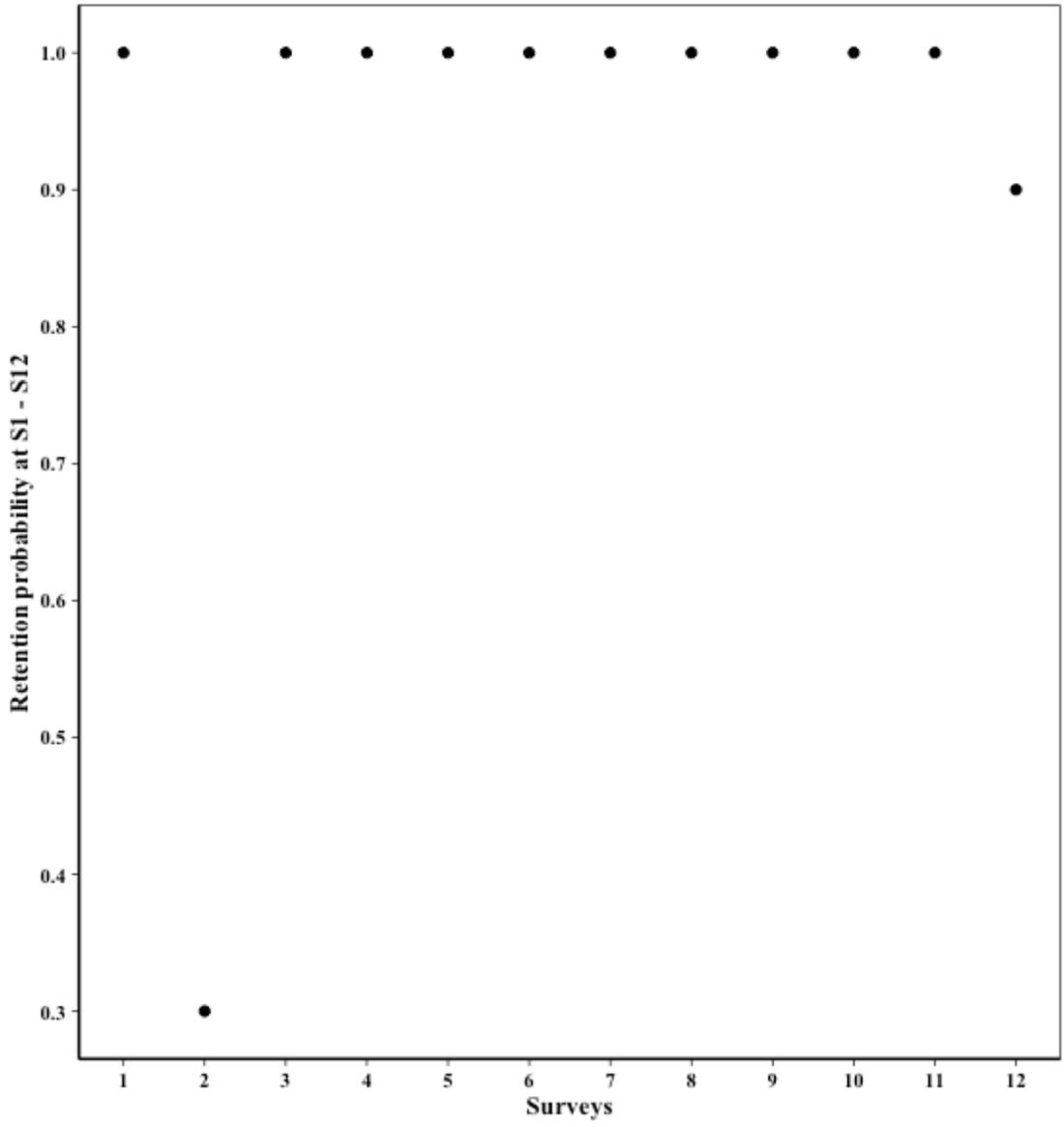


Figure 2

Retention Probability from Survey 1 – 12, based on the participants who have completed 12 surveys.

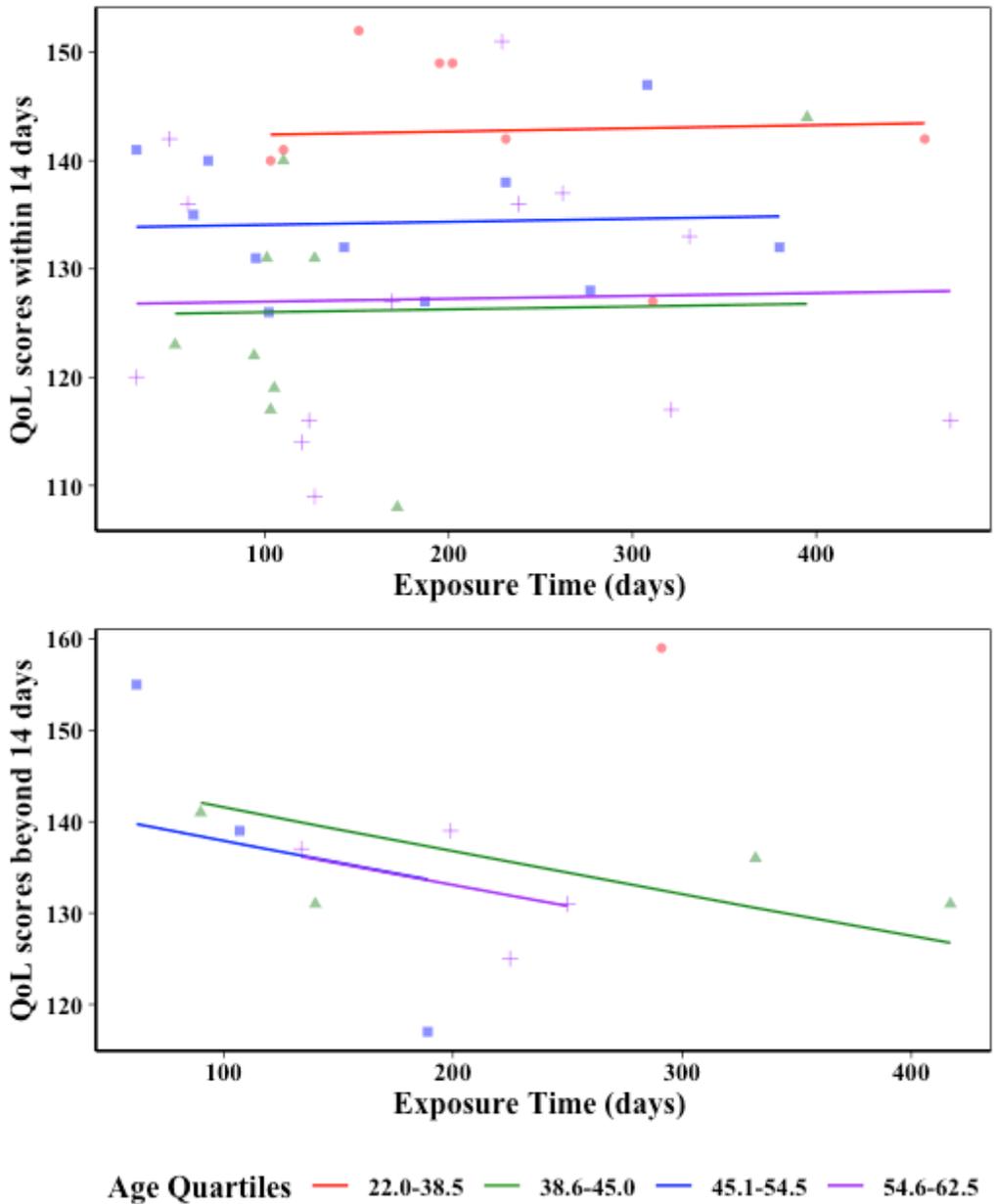


Figure 3

GLM Poisson regression model for UK-only long COVID-19 participants. Top panel: truncation time within 14 days. Bottom panel: truncation time beyond 14 days.

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- [SupplementaryMaterials.pdf](#)