Analysis of NHS Wales Long COVID Service User Data

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Contents

Abbreviations

AOR	Adjusted odds ratio	NICE	National Institute for Health and Care Excellence
EQ-5D	EuroQol-5 Dimension	ONS	Office for National Statistics
GP	General Practitioner	SD	Standard Deviation
IQR	Interquartile Range	UHB	University Health Board
LHB	Local Health Board	95% CI	95% Confidence Interval

1. Summary

- Cross-sectional survey data was collected between the 1st of September 2021 and the 31st of December 2022 from users of the various Long COVID services provided by the seven Local Health Boards (LHBs) in Wales, funded by Welsh Government's 'Adferiad' (Recovery) programme.

- This is the fourth report produced. Previously released reports, which contain descriptive results, can be found here: https://cedar.nhs.wales/our-work/evaluation/adferiad-recovery-long-covid-evaluation/. This report takes a different approach by aiming to assess uses changes and impact of Long COVID services over the data collection period. The extent of the analysis was restricted by limitations of the data.

- Collected data includes: responder demographics, Long COVID symptoms, the number of healthcare system interactions related to COVID-19 (primary, secondary and rehabilitation care), general quality of life (via the EQ-5D-5L), and service user experience feedback.

- Anonymous data collection meant it was not possible to follow individual patient responses as they progressed through the services. Instead, cross-sectional data at multiple points was collected. This comparative report considers the data collected at point of referral and at point of discharge.

- 1,921 completed or partially completed questionnaires at point of referral, and 507 at point of discharge were received. The majority were completed by female (N=1,625, 66.9%), of white ethnic origin (N=2,346, 96.6%) and generally did not have a hospital admission due to COVID-19 (N=1,820, 80.2%).

- Better scores were observed in the EQ-5D index, EQ-VAS and the EQ-5D-5L usual activities domain at point of referral compared to point of discharge. However, as data was not collected from non-service users, and the data that was collected was cross-sectional, it is not possible to directly conclude if this meant that patients improved, nor that any improvement was due to the service provision alone, or influenced by factors (e.g., natural disease progression).

- Hypothesis testing indicated that there were less people in full time employment and with different symptoms that accessed Long COVID services over the data collection period. However, it is possible that this is as a result of seasonal variations.

- It was observed that patient experiences of the service at discharge were very positive, and did not vary over time. However, care must be taken when interpreting these results due to low sample size which may not be representative of the population accessing the service on the whole.

- Future monitoring of the Long COVID recovery program should include a more robust and patient-identifiable data collection and assessment to fully understand the health and social benefits of this service.

2. Introduction

'Long COVID' refers to a wide range of signs and symptoms that persist or develop following acute COVID-19 illness caused by SARS-CoV-2 viral infection. Its current definition (NICE, 2021) encompasses:

- Ongoing symptomatic COVID-19: signs and symptoms for 4-12 weeks after infection
- Post COVID-19 syndrome: signs and symptoms for over 12 weeks after infection and not explained by an alternative diagnosis.

Long COVID is a complex condition currently not well understood. Its definition is constantly updated as new evidence emerges. It can present as either a single symptom, or one or more clusters of multiple symptoms, including (NIHR, 2021; Welsh Government, 2021): extreme tiredness ('fatigue'), shortness of breath, joint pain, change to sense of taste or smell, problems with memory and concentration ('brain fog'), sleep difficulties ('insomnia'), anxiety and depression, chest pain and many more. The cluster of symptoms can fluctuate, change over time and can affect any system in the body and cause wide spread autonomic dysfunction (Dani *et al.,* 2021).

Although there is still much uncertainty about its predisposing factors, a range of studies have reported that the risk of Long COVID increases in women, those who are overweight or obese, those who have been hospitalised because of COVID-19, those living in deprived areas, and those working in health and social care sectors (ONS, 2021; Sudre et al., 2021; Whitaker et al., 2021).

In the 4-week period ending on the 4th December 2022, the Office for National Statistics (ONS, 2022) estimated that 2.1 million people were experiencing self-reported Long COVID in the United Kingdom (UK). Of these, 9% had a suspected COVID-19 infection in the previous 12 weeks and 76% with symptoms that were adversely affecting their day-to-day activities (19.9% reported they were "limited a lot"). In the same ONS report an estimated 111,000 people in Wales self-reported Long COVID symptoms; 77% of them with subsequent day-to-day activity limitation.

Long COVID will continue to be associated with significant health and socio-economic harm for affected individuals, which negativity affects workforce contributions (ONS, 2021; Reuschke and Houston, 2022; Waters and Wernham, 2022), resulting in a further increase on the NHS workload (Welsh Government, 2021).

In response to this challenge, on the 15th of June 2021, the Welsh Minister for Health & Social Services announced the launch of the 'Adferiad' (Recovery) programme. This programme allocated £5 million to the seven Local Health Boards (LHBs) in Wales to introduce a new suite of patient pathways, combined with new or expanded primary and community rehabilitation services to support people with Long COVID.

Welsh Government is currently reviewing the 'Adferiad' (Recovery) programme every 6 months to monitor and assess the efficacy of the services provided, in line with any new emerging evidence for Long COVID treatment and management. The Executive Directors of Therapies and Health Science collectively supported and commissioned a national approach to the evaluation of the Long COVID services provided by the LHBs.

Cedar Health Technology Research Centre (https://cedar.nhs.wales/) and the Welsh Value in Health Centre (https://vbhc.nhs.wales/) have been supporting LHBs by providing a means for them to collect data from their own service users, and by providing data analysis and reporting for evaluation purposes. To date three national evaluation reports have been released to Welsh Government on the

14th of January (including data up to the 31st of December 2021), on the 30th of April 2022 (including data up to the 31st of March 2022) and on the 15th July 2022 (including data up to the 31st of May 2022). These reports have been published on Cedar's website (https://cedar.nhs.wales/our-work/evaluation/adferiad-recovery-long-covid-evaluation/). This fourth report follows on from these.

3. Aims and Objectives

No data was collected prior to the roll-out of the Long COVID services in Wales, which meant that comparisons directly assessing the benefit of services cannot made. Instead, the aim of this report is to attempt to evaluate the potential impacts of Long COVID services by:

- Exploring the potential impact that services may have had on patients' quality of life
- Assessing changes in the type of patients that accessed these services during the data collection period
- Assessing changes in service user experience during the data collection period

The objectives were therefore to attempt to answer the following questions:

1. Do patients at point of discharge have a better quality of life than those at point of referral?
2. Has the type of patients that are referred to the services changed over time?
3. Have discharged patients' service experience changed over time?

4. Methods

4.1 Data collection

Patient-reported data were collected between the 1st of September 2021 and the 31st of December 2022 via a secure web questionnaire (Online Surveys - https://www.onlinesurveys.ac.uk/), set up by Cedar and made available by the LHBs to their Long COVID service users. Each LHB received the same set of questionnaires which was available in English and Welsh. Hywel Dda UHB opted not to use the Online Survey system provided by Cedar, instead collecting data via an alternative platform (DrDoctor - https://www.drdoctor.co.uk/), and providing Cedar with their data at the end of the collection period. Aneurin Bevan UHB started by collecting data via Online Surveys, moving to DrDoctor in May 2022.

Patient identifiable data was not collected due to information governance concerns raised by LHBs that could not be resolved in the required timeframe due to the rapid roll out in September 2021. Anonymous data was therefore collected from five cohorts of Long COVID service users in Wales: existing service users as of September 1st 2021; new referrals; follow-ups; discharges; and others via social media. Health boards were instructed to ask their patients to complete questionnaires within a set timeframe for each service user groups (e.g., receipt of questionnaire at point of discharge). It is assumed that all LHBs did this accurately according to instruction, however, the likelihood that some patients may have received their questionnaire at different timepoints along the pathway must be acknowledged and considered. As this analysis only includes data collected at point of referral and discharge (Table 1), the data collection and management procedures specific to the other service user groups have not been detailed here, but can be found in previous reports.

Table 1. Definitions of data collection at point of referral and discharge

Service user group	Definition
New referrals	New referrals post 1st September 2021.
Discharge	Those discharged from the Long COVID service between the 6th of September 2021 and the 16th December 2022.

A combination of closed and open-ended questions (9.1 Appendi) was agreed with the Director of Therapies of each LHB to investigate the health status of Long COVID service users, along with their interaction with the service (**Error! Reference source not found.**).

Table 2. Questionnaire sections

Questionnaire section	Questions	Description	Administered to
Your Long COVID support	Question 0 (Q0)	Service users were explicitly asked which LHB they were referred to. This extra question was added to the survey on the 26th of January 2022	All groups
About you	Questions 1-4 (Q1-Q4)	Service user demographics	All groups
Your COVID-related health	Questions 5-8 (Q5-Q8, plus optional Q5a and Q6a)	COVID-19-related symptoms and numbers of encounters with healthcare services (primary care, secondary care and rehabilitation)	All groups
Your general health	Questions 9-14 (Q9-Q14)	The EQ-5D-5L health measures	All groups
About your experience	Questions 15-21 (Q15-Q21)	Service users' feedback with regards to their interactions with the Long COVID service	All groups except 'New referrals'

Returned questionnaires were excluded if (i) the health board could not be identified, or (ii) the patient explicitly declared that they did not have access to Long COVID services in free-text questions (i.e. Q0, Q19 or Q20). In total 10 (0.4 %) returned questionnaires were excluded from the analysis presented in this report.

4.2 The EQ-5D-5L

Q9-Q14 in the questionnaire represents the EQ-5D-5L (https://euroqol.org/), which measures the general quality of life of a person across five dimensions: mobility (Q9), self-care (Q10), usual activities (Q11), pain/discomfort (Q12) and anxiety/depression (Q13).

Responders chose one of five possible answers (levels) in each dimension. The responses to the five dimensions can be summarised as a unique score (the EQ-5D index), which corresponds to a health utility and represents quality of life (Van Hout et al., 2012). The EQ-5D index ranges from values <0 ('worse than dead') to 1 ('full health'), with an anchor at 0, which is equivalent to 'dead'.

The EQ-5D-5L also contains a visual analogue scale (EQ-VAS) (Q14) for responders to directly evaluate their own overall health at the time of response on a range of 0 (worst health imaginable) to 100 (best health imaginable).

4.3 Analysis

The responses from close-ended questions (i.e., those excluding Q6a, Q19 and Q20) were summarised as counts, percentages, medians and interquartile ranges, by both the new referrals and discharge groups.

Ordinal and linear regressions were undertaken to assess the difference in quality of life of discharged patients compared to referred patients (objective 1). The adjusted effect estimates (odds ratio, beta) and 95% confidence intervals (95% CI) were reported. Each regression was adjusted for age, gender, ethnicity and symptoms. Due to low counts in some categories, age groups containing those over 71 years of age, those of non-binary gender or preferred not to say, and those of ethnicities other than "white" were collapsed into single categories. Only statistically significant results are presented in this report.

Hypothesis testing was used to answer objectives 2 and 3, namely the Kruskal-Wallis H and Chi squared tests. Three three-month time windows (September – December 2021, April – June 2022, September – December 2022,) were used to make comparisons over time. The rationale for this was i) to allow more than two points with sufficient samples for longitudinal analysis, and ii) to evenly separate the points throughout the data collection period to maximise the likelihood of observing changes if any existed. If a significant result was found, pair-wise post-hoc comparisons were carried out using the Dunn's Test to identify significant differences between group pairs. Bonferroni correction was used to adjust the p-values, due to multiple comparisons. Significant results were plotted in stacked bar charts to illustrate any differences found between the three time points.

Statistical analyses were carried out using R statistical software (version 4.0.0) and RStudio integrated development environment (version 2020-04-24).

4.4 Limitations

Key limitations in both the data collection are outlined below.

1. Anonymous data collection
    - A patient's journey through the service could not be tracked
    - Multiple responses from one patient could not be accounted for
    - The referral and discharge groups were not directly comparable
    - Confirmation that the correct form was used at the correct time point was not possible
    - Confirmation that the responder actually accessed or used the Long COVID service was not possible
2. As the data is cross sectional it represents a snap shot in time and the time points chosen were based on data availability rather than for a clinical or service reasoning.
3. The small sample size (i.e. small number of completed questionnaires) means that not all potential confounding factors could be adjusted for (e.g., occupation).
4. The small sample size means that variation in LHB service provision could not be accounted for.

5. Results

5.1 Descriptive statistics

Between 1st September 2021 to the 31st December 2022 there were 1,921 responses to the referral questionnaire and 507 responses to the discharge questionnaire. Collected data was dominated by Cwm Taf Morgannwg UHB, with Powys Teaching Health Board supplying the lowest number of responses (Figure 1). The majority of respondents were females (N=1625, 66.9%), of white ethnic origin (N=2346, 96.6%) and did not have a hospital admission due to COVID-19 (N=1820, 80.2%) (Table 3). For those admitted to hospital following initial infection, the median stay was 7 days (IQR: 3-18) (Table 4). Overall, fatigue was the most commonly reported symptom (N=1,783, 73.4%) and having a fever the least reported (N=158, 6.5%) (Figure 2).

At referral the median EQ-5D index was 0.548 (IQR: 0.302-0.693), while at discharge it was higher at 0.642 (IQR: 0.25-0.760) (Table 5). Similarly, the EQ-VAS at referral was (50; IQR: 34-65), while it was (60; IQR: 41-80) at discharge.

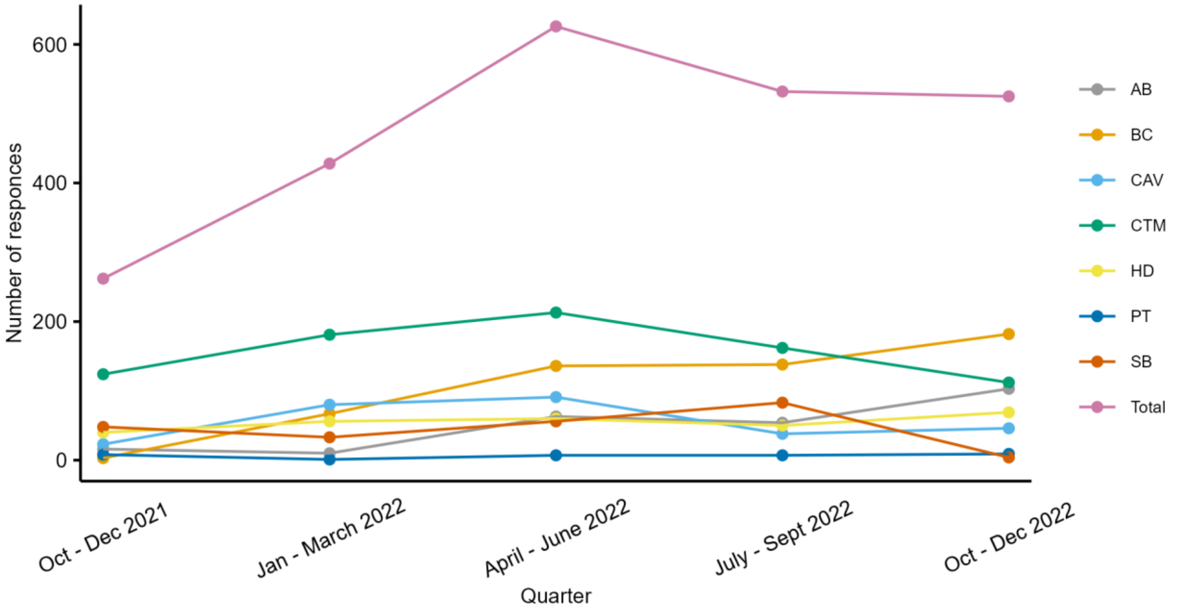

Figure 1 Number of responses received by health board for each quarter

Table 3 Demographics of responders to the referral and discharge questionnaire

	Referrals (N=1921) N(%)	Discharges (N=507) N(%)	Total (N=2428) N(%)
Health board			
Aneurin Bevan UHB	216 (11.2%)	31 (6.1%)	247 (10.2%)
Betsi Cadwaladr UHB	506 (26.3%)	20 (3.9%)	526 (21.7%)
Cardiff & Vale UHB	255 (13.3%)	27 (5.3%)	282 (11.6%)
Cwm Taf Morgannwg UHB	550 (28.6%)	291 (57.4%)	841 (34.6%)
Hywel Dda UHB	219 (11.4%)	56 (11.0%)	275 (11.3%)
Powys Teaching Health Board	19 (1.0%)	14 (2.8%)	33 (1.4%)
Swansea Bay UHB	156 (8.1%)	68 (13.4%)	224 (9.2%)
Age			
17 and under	2 (0.1%)	0 (0.0%)	2 (0.1%)
18 - 30	106 (5.5%)	24 (4.7%)	130 (5.4%)
31 - 40	304 (15.8%)	50 (9.9%)	354 (14.6%)
41 - 50	498 (25.9%)	119 (23.5%)	617 (25.4%)
51 - 60	579 (30.1%)	182 (35.9%)	761 (31.3%)
61 - 70	325 (16.9%)	97 (19.1%)	422 (17.4%)
71 - 80	103 (5.4%)	33 (6.5%)	136 (5.6%)
81 - 90	4 (0.2%)	2 (0.4%)	6 (0.2%)
91 and over	0 (0.0%)	0 (0.0%)	0 (0.0%)
Gender			
Female	1314 (68.4%)	311 (61.3%)	1625 (66.9%)
Male	601 (31.3%)	193 (38.1%)	794 (32.7%)
Non-Binary	1 (0.1%)	0 (0.0%)	1 (0.0%)
Prefer not to say	5 (0.3%)	3 (0.6%)	8 (0.3%)
Ethnicity			
Any White background	1850 (96.3%)	496 (97.8%)	2346 (96.6%)
Gypsy or Irish Traveller	2 (0.1%)	0 (0.0%)	2 (0.1%)
White and Black Caribbean	5 (0.3%)	0 (0.0%)	5 (0.2%)
White and Black African	3 (0.2%)	0 (0.0%)	3 (0.1%)
White and Asian	7 (0.4%)	3 (0.6%)	10 (0.4%)
Any other mixed background	10 (0.5%)	2 (0.4%)	12 (0.5%)
Indian	8 (0.4%)	0 (0.0%)	8 (0.3%)
Pakistani	8 (0.4%)	0 (0.0%)	8 (0.3%)
Bangladeshi	2 (0.1%)	0 (0.0%)	2 (0.1%)
Chinese	1 (0.1%)	0 (0.0%)	1 (0.0%)
Any other Asian background	9 (0.5%)	2 (0.4%)	11 (0.5%)
Caribbean	2 (0.1%)	0 (0.0%)	2 (0.1%)
African	4 (0.2%)	0 (0.0%)	4 (0.2%)
Any other Black background	0 (0.0%)	0 (0.0%)	0 (0.0%)
Arab	0 (0.0%)	0 (0.0%)	0 (0.0%)
Any other ethnic group	3 (0.2%)	1 (0.2%)	4 (0.2%)
Prefer not to say	7 (0.4%)	3 (0.6%)	10 (0.4%)
Admitted to hospital due to COVID-19			
Yes	333 (18.6%)	88 (18.4%)	421 (18.6%)
No	1440 (80.4%)	380 (79.7%)	1820 (80.2%)
Not sure	18 (1.0%)	9 (1.9%)	27 (1.2%)
Unanswered	130	30	160

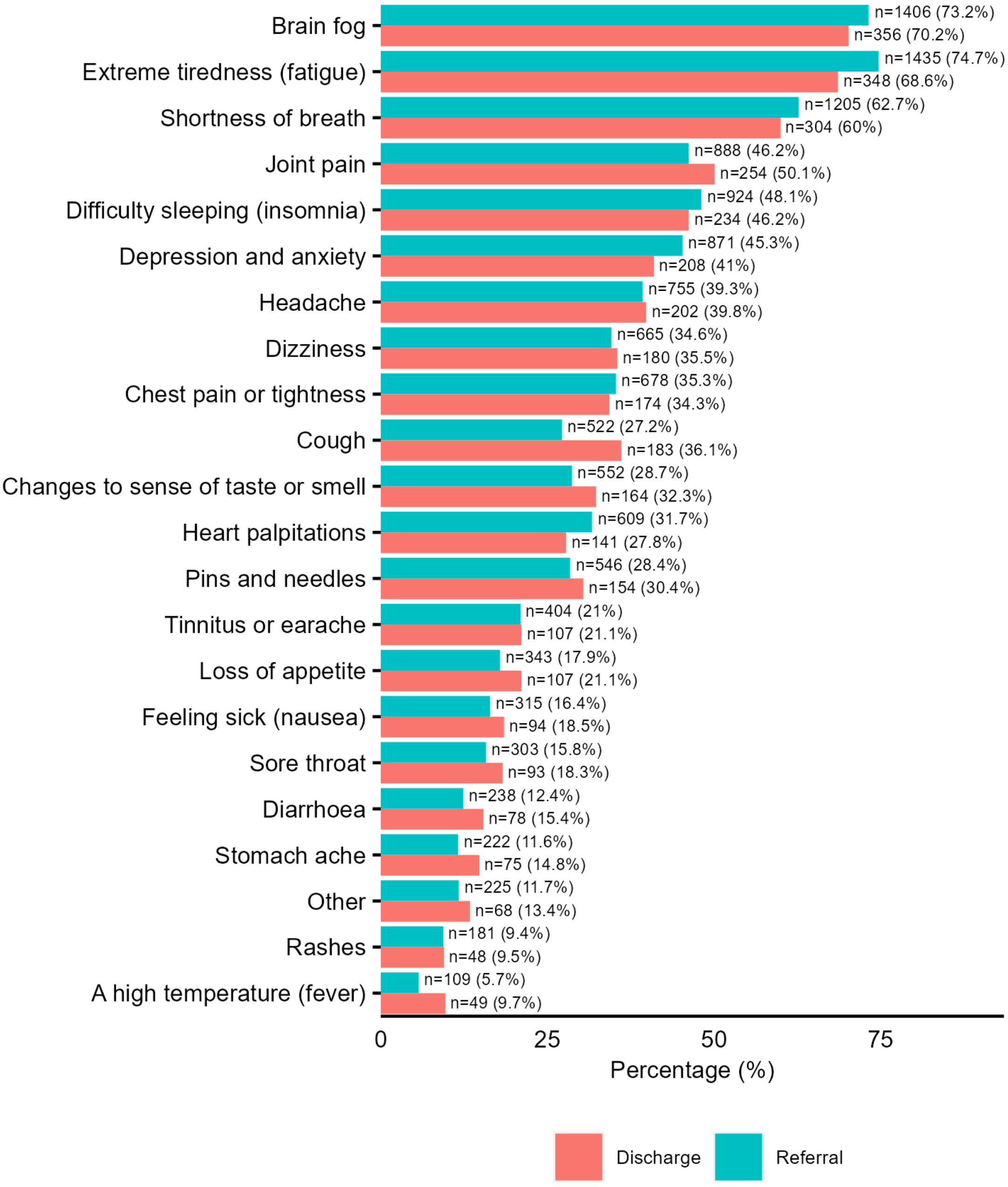

Figure 2 Self-reported symptoms at time point of referral and discharge

Table 4 Self-reported healthcare usage by responders

	Referrals (N=1921)	Discharges (N=507)	Total (N=2428)
Admitted to hospital due to COVID-19			
Yes	333 (18.6%)	88 (18.4%)	421 (18.6%)
No	1440 (80.4%)	380 (79.7%)	1820 (80.2%)
Not sure	18 (1.0%)	9 (1.9%)	27 (1.2%)
Unanswered	130	30	160
Number of days in hospital			
Mean (SD)	14.932 (23.339)	29.819 (45.259)	17.983 (29.745)
Median (IQR)	7.000 (2.000, 15.000)	12.000 (5.500, 34.000)	7.000 (3.000, 18.000)
Unanswered	28	7	35
Number of GP visits in the last 6 months			
Mean (SD)	4.784 (5.018)	4.571 (6.463)	4.738 (5.359)
Median (IQR)	4.000 (2.000, 6.000)	3.000 (1.000, 6.000)	4.000 (2.000, 6.000)
Unanswered	175	32	207
Number of rehab session related to your COVID-19			
Mean (SD)	1.451 (3.244)	5.676 (5.173)	2.523 (4.244)
Median (IQR)	1.000 (0.000, 1.000)	4.000 (2.000, 8.000)	1.000 (0.000, 3.000)
Unanswered	585	53	638

Abbreviations: SD = standard deviation, IQR = interquartile ranges

Table 5 Quality of Life responses at point of referral and discharge

	Referrals (N=1921)	Discharges (N=507)	Total (N=2428)
EQ-5D-5L Mobility responses			
I have no problems in walking about	510 (26.5%)	161 (31.8%)	671 (27.6%)
I have slight problems in walking about	514 (26.8%)	145 (28.6%)	659 (27.1%)
I have moderate problems in walking about	616 (32.1%)	143 (28.2%)	759 (31.3%)
I have severe problems in walking about	275 (14.3%)	56 (11.0%)	331 (13.6%)
I am unable to walk about	6 (0.3%)	2 (0.4%)	8 (0.3%)
EQ-5D-5L Self-Care responses			
I have no problems washing or dressing myself	1089 (56.7%)	304 (60.0%)	1393 (57.4%)
I have slight problems washing or dressing myself	395 (20.6%)	98 (19.3%)	493 (20.3%)
I have moderate problems washing or dressing myself	330 (17.2%)	81 (16.0%)	411 (16.9%)
I have severe problems washing or dressing myself	97 (5.0%)	22 (4.3%)	119 (4.9%)
I am unable wash or dress myself	10 (0.5%)	2 (0.4%)	12 (0.5%)
EQ-5D-5L Usual Activities responses			
I have no problems doing my usual activities	95 (4.9%)	82 (16.2%)	177 (7.3%)
I have slight problems doing my usual activities	414 (21.6%)	121 (23.9%)	535 (22.0%)
I have moderate problems doing my usual activities	733 (38.2%)	182 (35.9%)	915 (37.7%)
I have severe problems doing my usual activities	460 (23.9%)	74 (14.6%)	534 (22.0%)
I am unable to do my usual activities	219 (11.4%)	48 (9.5%)	267 (11.0%)
EQ-5D-5L Pain/Discomfort responses			
I have no pain or discomfort	267 (13.9%)	103 (20.3%)	370 (15.2%)
I have slight pain or discomfort	466 (24.3%)	142 (28.0%)	608 (25.0%)
I have moderate pain or discomfort	724 (37.7%)	162 (32.0%)	886 (36.5%)
I have severe pain or discomfort	390 (20.3%)	81 (16.0%)	471 (19.4%)
I have extreme pain of discomfort	74 (3.9%)	19 (3.7%)	93 (3.8%)
EQ-5D-5L Anxiety/Depression responses			
I am not anxious or depressed	304 (15.8%)	151 (29.8%)	455 (18.7%)
I am slightly anxious or depresses	578 (30.1%)	158 (31.2%)	736 (30.3%)
I am moderately anxious or depressed	656 (34.1%)	130 (25.6%)	786 (32.4%)
I am severely anxious or depressed	274 (14.3%)	47 (9.3%)	321 (13.2%)
I am extremely anxious or depressed	109 (5.7%)	21 (4.1%)	130 (5.4%)
EQ5D index			
Median (IQR)	0.548 (0.302, 0.693)	0.642 (0.325, 0.760)	0.560 (0.304, 0.711)
EQ-VAS			
Median (IQR)	50.0 (34.00, 65.0)	60.0 (41.0, 80.0)	50.0 (35.0, 70.0)
Unanswered	0	2	2

5.2 Do patients at point of discharge have a better quality of life than those at point of referral?

Regression analyses with confounder adjustment for age, gender, ethnicity and symptoms was undertaken with the EQ-5D index (quality of life score), EQ-VAS (direct indication of overall health) and the EQ-5D-5L Usual Activities domain as dependent variables. It was not possible to do this for the other four domains in the EQ-5D-5L due to low sample sizes in the outcome variable (Table 5) or in important confounding variables.

Results showed that patients at referral were observed to have a lower EQ-5D index (β: -0.08; 95%CI: -0.10 – -0.05) than discharged patients (Table 6). Other contributors to lower scores were being older, having depression and anxiety, loss of appetite, joint pain, brain fog, dizziness, diarrhoea, shortness of breath, chest pain and tinnitus. Unexpectedly, having fatigue or rashes contributed to a higher EQ-5D index compared to those without symptoms (Appendix 2).

The EQ-VAS was also observed to be lower in patients at point of referral (β: -9.83; 95%CI: -11.81 – -7.85) compared to patients at discharge (Table 6). In addition, being older, ethnicity, and having brain fog, depression and anxiety, stomach ache, diarrhoea, dizziness, joint pain, loss of appetite and chest pain all contributed to having a worse EQ-VAS (Appendix 2).

Patients at referral (AOR: 1.96; 95% CI: 1.63 – 2.36) were also more likely to be unable to complete their usual daily activities compared to those at point of discharge (Table 6). However, results also showed that older patients are more likely to be unable to complete their daily activities, in addition to those with brain fog, depression and anxiety, loss of appetite, shortness of breath, fatigue, chest pain, dizziness and pins and needles (Appendix 2).

Table 6 Effect estimate for the difference in quality of life between discharged patients and referral patients

Ordinal regression			
	Adjusted Odds Ratios	*95% CI*	*P value*
Usual activities	1.96	1.63 – 2.36	**<0.001**
Linear regression			
	Adjusted β	*95% CI*	*P value*
EQ-5D index	-0.08	-0.10 – -0.05	**<0.001**
EQ-VAS	-9.83	-11.81 – -7.85	**<0.001**

Referrals were compared to discharges (reference group)
Abbreviations: 95% CI – 95% confidence interval.
*Please note that the EQ-5D index and EQ-VAS are measured on different scales, therefore the β coefficient cannot be compared directly.

5.3 Has the type of patients that are referred to the services changed over time?

There were 228 responses at point of referral across all LHBs between October and December 2021, 517 between April and June 2022, and 402 between October and December 2022. Hypothesis testing indicated that there was a lower proportion of patients being referred during the collection period who were in full time employment (H: 15.4; p <0.001) (Figure 3).

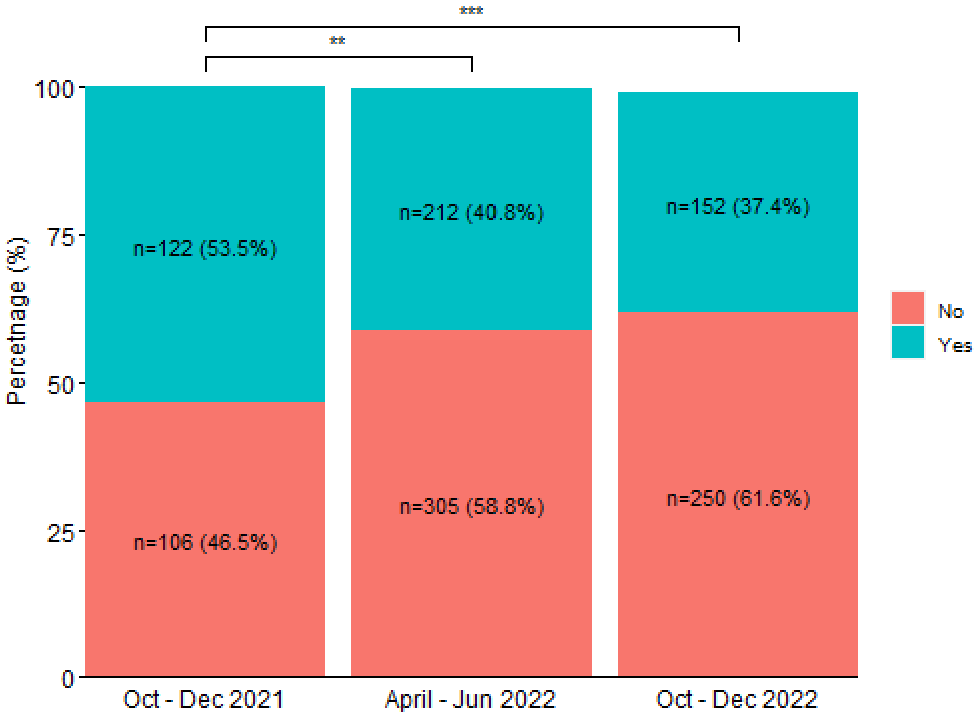

Figure 3 Stacked bar chart of the number of referred patients that were in full time employment at three time points during the data collection period

Symptoms with statistically significant differences across any of the time points included: change of taste and smell (χ^2 6.41; p=0.041), cough (χ^2 8.5; p=0.014), depression (χ^2 14.89; p=0.0101), dizziness (χ^2 13.74; p=0.001), heart palpitations (χ^2 11.88; p=0.003), loss of appetite (χ^2 9.84; p=0.007), brain fog (χ^2 23; p <0.001), fatigue (χ^2 6.67; p=0.037) and other symptoms (χ^2 7.9; p0.019) (Figure 4). While the proportion of self-reported occurrence of these symptoms were observed to change over the three time points, there was no consistent direction of change (some increasing, some decreasing and some fluctuating) (Figure 4). All non-statistically significant results are listed in Appendix 3.

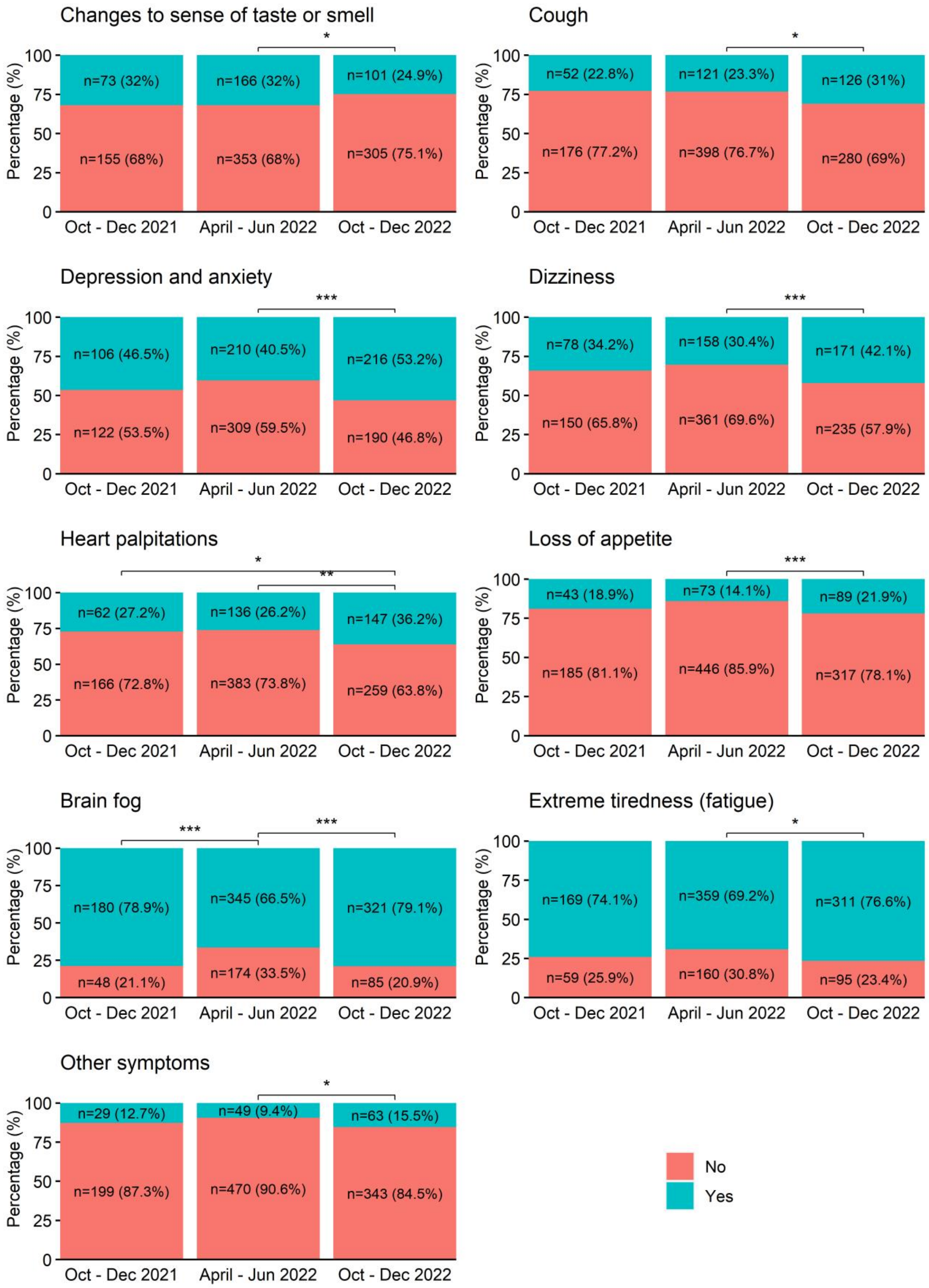

Figure 4 Stacked bar chart of symptoms reported by patients at referral across three time points

Abbreviations: Brackets represent statistically significant difference. * = p≤0.05, ** = p≤0.01, *** = p≤0.001

5.4 Have discharged patients' service experience changed over time?

Service experience score was very positive at point of discharge, with a median score of 9/10 (IQR: 5.8-10) between October and December 2021, 9/10 (IQR:7-10) between April and June 2022, and 8/10 (IQR: 5-10) between October and December 2022. A Kruskal Wallis hypothesis test showed that there was no statistically significant difference in the overall service experience score (Q18) between September 2021 and December 2022 (H: 0.53; p=0.466). Unfortunately, due to a low number of responses, hypothesis testing could not be undertaken on the other service experience questions (i.e. listening (Q15), being supported (Q17), being involved (Q18) and for service recommendation (Q21)) (Appendix 4).

6. Discussion

This report has taken a comparative approach to evaluate the service over time. The analysis was limited by the lack of patient identifiable data, resulting in the inability to link patient data in order to follow-up individuals over time. Furthermore, patients could have completed multiple questionnaires at different time points. An attempt to mitigate against this was undertaken by only including referrals and discharges; based on the assumption that a patient would only complete a referral or discharge questionnaire once each. More robust analysis may have been achievable with the collection of patient identifiable data, and should be considered for any further evaluation of the Long COVID services in Wales.

In the context of these limitations there was **some** suggestion that:

1. Quality of life was better for patients at discharge compared to those at referral.

However, as data collection did not follow patients during their Long COVID service journey, it was not possible to determine whether patients had *improved* between point of referral and point of discharge. Furthermore, as non-service users were not included within this study, it was not possible to determine whether any potential improvement was a direct result of the services provided. Results also showed that age and symptoms of brain fog, depression and anxiety, loss of appetite, chest pain and dizziness, were all factors that negatively affected quality of life outcomes. This highlights the need to follow patients throughout their service journey in order to correct for confounders to determine whether or not services improved quality of life. It should also be noted that the 51-60 years age group was the largest age group accessing Long COVID services, and these also had lower quality of life scores. This finding is unsurprising given that middle-aged individuals are at greatest risk of not recovering fully following COVID-19 infection (Crook *et al.,* 2021).

2. There were changes in Long COVID symptom presentation at point of referral over the course of the time period studied.

Symptom variation could be an artefact of the change in COVID-19 strains of virus across the study period, and vaccination uptake, neither of which could be adjusted for with this analysis (as this information was not collected). Furthermore, it was not possible to identify any possible seasonal variations in symptom presentation due to the snap shots of time used. True seasonal variation in symptom presentation may be unlikely, as previous studies into similar conditions such as chronic fatigue found that there was even less seasonal variation in symptom presentation than the general population (García-Borreguero *et al.,* 1998). There may also be changes in symptom presentation of Long COVID, due to the natural progression of the disease and some patients presenting later than others; which may be reflected in the higher proportion of self-reported heart palpitations across the three time periods. Further research into seasonal variation and potential changes in Long COVID, is required, to add context to these results.

3. There were less people in full time employment accessing Long COVID services in Wales at the end of the data collection period than at the beginning.

However, as it was not possible to determine whether the sample of patients who completed questionnaires was representative of the population accessing Long COVID services in Wales, it was subsequently not possible to conclude that this employment status trend was true of the population.

4. There was no change in overall service user experiences at point of discharge across the time period.

The analysis was undertaken at the national level to provide the greatest statistical power, but it's likely that there are variations in outcomes by health board. Health boards either set up a new service or integrated into existing services, resulting in a variation in the type of service provided. Services ranged widely including the provision of information (e.g., leaflets), appointment with physiotherapists/psychologists, group sessions, specialist consultant appointments and advice for GPs to manage patients in primary care. As there was no national definition of who qualified for access to Long COVID services in Wales it is likely that there is variation among the patients accessing services at different health boards, consequently leading to additional inconsistency in the data collected. Future characterisation of Long COVID syndrome, through clinical characterisation (Crook *et al.,* 2021), and development of refined and nationally agreed treatment options would enable a more informed evaluation of Long COVID service provision.

In addition, there was significant variation in the amount of data received at each LHB, with some providing significant sample sizes in some months but very low numbers in others (Figure 1). While variation in sample size was expected between LHBs, without patient identifiable data or demographic data of service users who did not complete the questionnaire, it was not possible to determine whether the data received was representative of the patient population who accessed Long COVID services in Wales. As the reasons for non-response could not be determined, this potentially means that those with more severe symptoms/burden may have either dominated or been under represented in the data. Many patients seen within the Long COVID service may be the more severe cases, and therefore the type of patients and benefits seen may not be generalisable to the entire Long COVID population. Furthermore, due to the lack of diagnostic testing for Long COVID, some patients will have also been by departments in other specialities (e.g., neurology, general medicine, cardiology) and some may have been missed from this sample. Conversely, some of the patients within the Long COVID service may have other chronic conditions (e.g., fibromyalgia, Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome), in addition to or instead of Long COVID, especially when there has not been a confirmed COVID-19 diagnosis. Drawing parallels between Long COVID services and that of other chronic conditions may be appropriate (Wong *et al.,* 2021, Crook *et al.,* 2021), and could be used for service improvements in both areas.

Although this study does not explore the health economic benefit of the Long COVID service, there are known health and socioeconomic impacts of Long COVID (Crook *et al.,* 2021). A small-scale investigation undertaken by Welsh Government using a sample of the data collected as part of this programme of work indicated that there are health economic impacts of Long COVID (Collins *et al.,* unpublished personal communication). Therefore, any patient-reported improvement could have a health economic benefit, but further investigation is required to quantify any health economic benefits the Long COVID service provides.

7. Conclusion

This provides information of the impact and usage of Long COVID services in between 1st September 2021 and 31st December 2022. Limitations with the data and a lack of a comparator group made it not possible to directly determine whether services have had a positive impact on patients. However, data analysis suggested that i) quality life scores collected from patients at point of discharge was higher than those collected at point of referral; ii) there are less people in full time employment and with different symptoms access Long COVID services at the end of the data collection period than at the beginning; and iii) service user experience was positive throughout the data collection period (with no observed changes over time).

It is recommended that patient identifiable data collection with a potential comparator group is implemented for robust evaluation of Long COVID services in Wales.

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9. Appendices

9.1 Appendix 1: Service user questionnaire

A.1.1 Section 'Your Long COVID support' [Q0]

Q0. Please tell us which Health Board you have been referred to for support for your Long COVID

☐ Aneurin Bevan University Health Board

☐ Betsi Cadwaladr University Health Board

☐ Cardiff & Vale University Health Board

☐ Cwm Taf Morgannwg University Health Board

☐ Hywel Dda University Health Board

☐ Powys Teaching Health Board

☐ Swansea Bay University Health Board

☐ A Health Board outside of Wales

☐ I don't know

☐ I have not been referred for support

Q0a. If you answered "I don't know" or "I have not been referred for support" to the question above, please tell us where you live. N.B. Please note, some of the following questions may not be applicable to you.

____

A.1.2 Section 'About you' (Q1-Q4)

Please answer the following questions so we know a little bit more about you. This will help us link your feedback to understand how your responses change over time.

Q1. Please tell us your age range

☐ 17 and under

☐ 18 - 30

☐ 31 - 40

☐ 41 - 50

☐ 51 - 60

☐ 61 - 70

☐ 71 - 80

☐ 81 - 90

☐ 91 and over

Q2. Please tell us your gender

☐ Male

☐ Female

☐ Non-Binary

☐ Prefer not to say

Q3. Please tell us your ethnic group

☐ Any White background including Welsh, English, Scottish, Northern Irish, British, Irish

☐ Gypsy or Irish Traveller

☐ White and Black Caribbean

☐ White and Black African

☐ White and Asian

☐ Any other mixed background / multiple ethnic background

☐ Indian

☐ Pakistani

☐ Bangladeshi

☐ Chinese

☐ Any other Asian background

☐ Caribbean

☐ African

☐ Any other Black background

☐ Arab

☐ Any other ethnic group

☐ Prefer not to say

Q4. Which of these describe your employment status? (Please select all that apply)

☐ Full-time employed or self-employed

☐ Student

☐ Part-time employed or self-employed

☐ Retired

☐ Unemployed / seeking work

☐ Long-term sick

☐ Looking after home or family

☐ Disabled

☐ Other

A.1.3 Section ‘Your COVID-related health’ (Q5-Q8)

Q5. Have you been admitted to hospital as an in-patient as a result of COVID-19?

☐ Yes

☐ No

☐ Not sure

Q5a. If yes, in total, how many days did you spend in hospital? (If you are still in hospital, please tell us how many days you have been in hospital so far).

Q6. Please tell us about any symptoms you have experienced today due to COVID-19 (Please select all that apply)

(Note: the list of symptoms was retrieved from https://www.nhs.uk/conditions/coronavirus-covid-19/long-term-effects-of-coronavirus-long-covid/)

☐ Extreme tiredness (fatigue)

☐ Difficulty sleeping (insomnia)

☐ Shortness of breath

☐ Pins and needles

☐ Chest pain or tightness

☐ Joint pain

☐ Heart palpitations

☐ Depression and anxiety

☐ Dizziness

☐ Tinnitus or earache

☐ Rashes

☐ Feeling sick (nausea)

☐ Diarrhoea

☐ Stomach ache

☐ Loss of appetite

☐ A high temperature (fever)

☐ Cough

☐ Headache

☐ Problems with memory and concentration (‘brain fog’)

☐ Changes to sense of taste or smell

☐ Sore throat

☐ Other

Q6a. If other, please specify

____

Q7. Please tell us how many GP visits/contacts (face-to-face or remotely) you have had in the last 6 months related to COVID-19

____

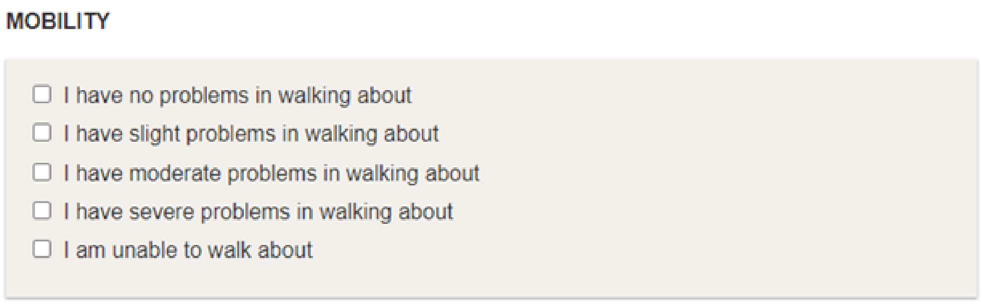
Q8. If you have had rehabilitation related to your COVID-19, please tell us how many sessions/appointments you have had.

____

A.1.4 Section ‘Your general health’ (Q9-14)

This section (Q9-Q14) contains the EQ-5D-5L tool. © EuroQol Research Foundation. EQ-5D™ is a trade mark of the EuroQol Research Foundation UK (English) v2.1.

Q9. Please select the ONE box that best describes your health TODAY: MOBILITY



MOBILITY

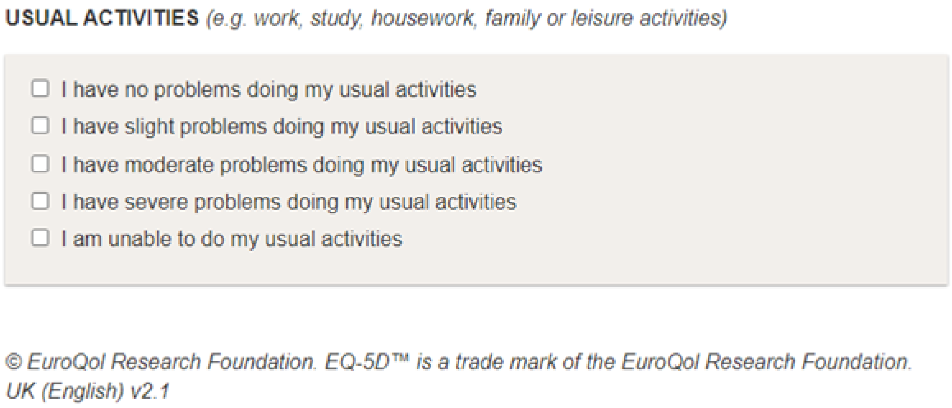
☐ I have no problems in walking about
☐ I have slight problems in walking about
☐ I have moderate problems in walking about
☐ I have severe problems in walking about
☐ I am unable to walk about

Q10. Please select the ONE box that best describes your health TODAY: SELF-CARE

SELF-CARE

☐ I have no problems washing or dressing myself
☐ I have slight problems washing or dressing myself
☐ I have moderate problems washing or dressing myself
☐ I have severe problems washing or dressing myself
☐ I am unable to wash or dress myself

Q11. Please select the ONE box that best describes your health TODAY: USUAL ACTIVITIES



USUAL ACTIVITIES *(e.g. work, study, housework, family or leisure activities)*

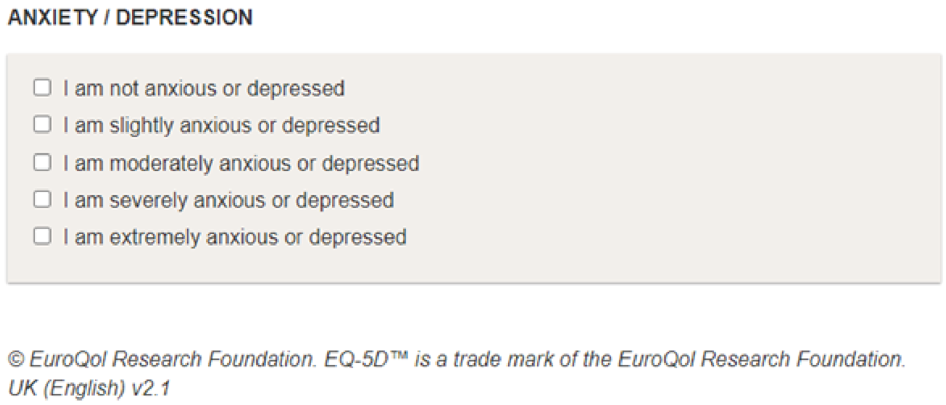
☐ I have no problems doing my usual activities
☐ I have slight problems doing my usual activities
☐ I have moderate problems doing my usual activities
☐ I have severe problems doing my usual activities
☐ I am unable to do my usual activities

Q12. Please select the ONE box that best describes your health TODAY: PAIN / DISCOMFORT

PAIN / DISCOMFORT

☐ I have no pain or discomfort
☐ I have slight pain or discomfort
☐ I have moderate pain or discomfort
☐ I have severe pain or discomfort
☐ I have extreme pain or discomfort

Q13. Please select the ONE box that best describes your health TODAY: ANXIETY / DEPRESSION



ANXIETY / DEPRESSION

☐ I am not anxious or depressed
☐ I am slightly anxious or depressed
☐ I am moderately anxious or depressed
☐ I am severely anxious or depressed
☐ I am extremely anxious or depressed

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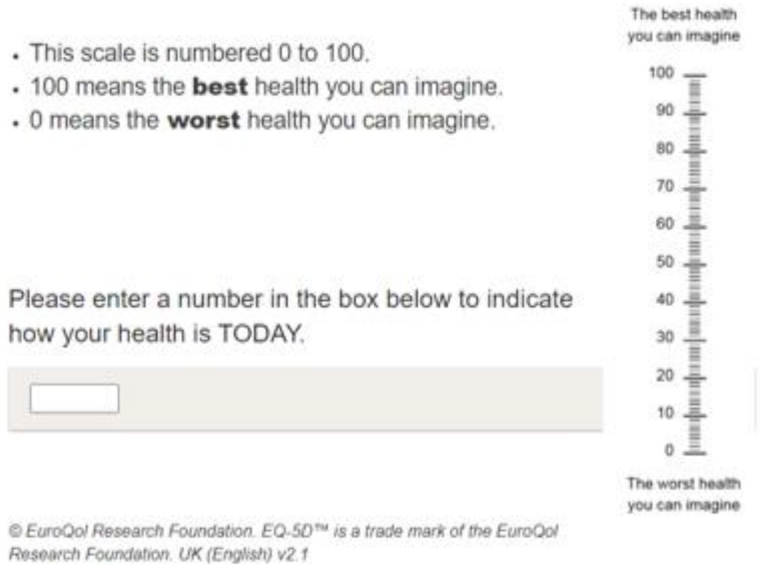
Q14. We would like to know how good or bad your health is today



- This scale is numbered 0 to 100.
- 100 means the **best** health you can imagine.
- 0 means the **worst** health you can imagine.

Please enter a number in the box below to indicate how your health is TODAY.

☐

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A.1.5 Section ‘About your experience’ (Q15-21)

Thinking about your overall first impressions of the Post COVID-19 Syndrome (Long COVID) Service:

Q15. Did you feel your concerns were listened to and understood?

☐ Always

☐ Usually

☐ Sometimes

☐ Never

Q16. Were you supported to get the information and help you needed?

☐ Always

☐ Usually

☐ Sometimes

☐ Never

Q17. Were you involved enough in deciding what support you received?

☐ Always

☐ Usually

☐ Sometimes

☐ Never

Q18. Using a scale of 0-10 where 0 is very bad and 10 is excellent, how would you rate your overall experience?

0 (Very Bad) 1 2 3 4 5 (Average) 6 7 8 9 10 (Excellent)

Thinking of your responses:

Q19. Please tell us if there was anything particularly good about your experiences that you would like to tell us about?

Q20. Please tell us if there is anything that we could change to improve your experience?

Q21. Would you recommend this service?

☐ Yes

☐ No

Q22. Please tell us roughly how long ago you were referred to the Long COVID Service at your local Health Board?

☐ I have not been referred

☐ Up to 1 month ago

☐ Between 1 month and 3 months ago

☐ More than 3 months ago

☐ I do not remember

☐ I am not sure if I have been referred

Q23. Please tell us which one of the following options applies to you: (mandatory)

☐ I have not been referred to the Long COVID Service

☐ I am waiting to receive my first appointment/support from the Long COVID Service

☐ I am still attending appointments/receiving support from the Long COVID Service

☐ I have been discharged from the Long COVID Service

These two extra questions were used to categorise the social media responders into service user groups (the 'Existing service users' category was not considered because the survey on social media was released more than 6 months since the start of the Adferiad programme). The logic used is explained in the table below:

Service user group category	Q22	Combination (Q22/Q23)	Q23
New referrals	'Up to 1 month ago' **or** 'Between 1 month and 3 months ago'	**And not**	'I have been discharged from the Long COVID Service'
Follow-up	'More than 3 months ago'	**And**	'I am still attending appointments/receiving support from the Long COVID Service'
Discharged	*Any response choice*	**And**	'I have been discharged from the Long COVID Service'
Additional responders	'I have not been referred'	**Or**	'I have not been referred to the Long COVID Service' **Or** 'I am waiting to receive my first appointment/support from the Long COVID Service'

9.2 Appendix 2: Full results for section 5.2: Do patients at point of discharge have a better quality of life than those at point of referral?

Ordinal regression analysis for the association between the EQ-5D-5L usual activities score and referral and discharge.

	EQ-5D-5L usual activities (N = 2429)		
Predictors	*AOR*	*95% CI*	*p*
Pathway stage (Ref: Discharge)			
Referral	1.96	1.63 – 2.36	**<0.001**
Age range [years] (Ref: Under 30)			
31 – 40	1.62	1.11 – 2.37	**0.012**
41 - 50	1.95	1.36 – 2.79	**<0.001**
51 - 60	2.26	1.59 – 3.22	**<0.001**
61 - 70	2.01	1.39 – 2.93	**<0.001**
71 and over	1.52	0.97 – 2.40	0.069
Gender (Ref: Female)			
Male	1.08	0.92 – 1.26	0.353
Ethnicity (Ref: White)			
Other	1.09	0.72 – 1.64	0.690
Symptoms (Ref: No)			
Fatigue: Yes	1.30	1.05 – 1.61	**0.018**
Shortness breath: Yes	1.36	1.13 – 1.63	**0.001**
Chest pain: Yes	1.28	1.07 – 1.53	**0.006**
Heart palpitations: Yes	0.94	0.79 – 1.13	0.515
Dizziness: Yes	1.26	1.05 – 1.50	**0.012**
Rashes: Yes	0.69	0.54 – 0.90	**0.005**
Diarrhoea: Yes	1.22	0.96 – 1.56	0.108
Loss appetite: Yes	1.37	1.11 – 1.68	**0.003**
Cough: Yes	0.80	0.67 – 0.96	**0.017**
Brain fog: Yes	1.71	1.43 – 2.04	**<0.001**
Sore throat: Yes	1.14	0.92 – 1.41	0.238
Insomnia: Yes	0.92	0.77 – 1.09	0.318
Pins needles: Yes	1.22	1.02 – 1.47	**0.031**
Joint pain: Yes	1.13	0.95 – 1.35	0.164
Depression anxiety: Yes	1.38	1.16 – 1.64	**<0.001**
Tinnitus: Yes	1.06	0.87 – 1.28	0.565
Nausea: Yes	1.18	0.94 – 1.48	0.156
Stomach ache: Yes	0.93	0.72 – 1.20	0.571

Abbreviations: AOR: Adjusted odds ratio. 95% CI – 95% Confidence interval, p = p value. Bold results are statistically significant to p<0.05.

Linear analysis for the association between the EQ-VAS and referral and discharge.

	EQ-VAS (N = 2427)		
Predictors	β	*95% CI*	*p*
Intercept	72.94	68.80 – 77.08	**<0.001**
Pathway stage (Ref: Discharge)			
Referral	-9.83	-11.81 – -7.85	**<0.001**
Age range [years] (Ref: Under 30)			
31 – 40	-1.53	-5.56 – 2.50	0.456
41 - 50	-3.71	-7.51 – 0.09	0.056
51 - 60	-4.21	-7.96 – -0.46	**0.028**
61 - 70	-3.38	-7.36 – 0.60	0.096
71 and over	-0.42	-5.22 – 4.37	0.863
Gender (Ref: Female)			
Male	0.38	-1.35 – 2.10	0.668
Ethnicity (Ref: White)			
Other	-5.57	-10.00 – -1.13	**0.014**
Symptoms (Ref: No)			
Fatigue: Yes	0.06	-2.26 – 2.39	0.957
Shortness breath: Yes	-0.54	-2.56 – 1.48	0.600
Chest pain: Yes	-2.03	-4.00 – -0.07	**0.043**
Heart palpitations: Yes	0.63	-1.35 – 2.62	0.531
Dizziness: Yes	-2.70	-4.66 – -0.75	**0.007**
Rashes: Yes	1.35	-1.50 – 4.20	0.354
Diarrhoea: Yes	-3.05	-5.71 – -0.39	**0.025**
Loss appetite: Yes	-2.33	-4.60 – -0.06	**0.045**
Cough: Yes	1.24	-0.73 – 3.22	0.217
Brain fog: Yes	-5.29	-7.21 – -3.37	**<0.001**
Sore throat: Yes	-2.29	-4.69 – 0.11	0.061
Insomnia: Yes	-1.00	-2.87 – 0.86	0.292
Pins needles: Yes	-1.27	-3.27 – 0.72	0.211
Joint pain: Yes	-2.34	-4.26 – -0.42	**0.017**
Depression anxiety: Yes	-3.86	-5.77 – -1.95	**<0.001**
Tinnitus: Yes	-0.71	-2.83 – 1.41	0.512
Nausea: Yes	-0.98	-3.48 – 1.53	0.444
Stomach ache: Yes	-3.28	-6.10 – -0.47	**0.022**

Abbreviations: 95% CI – 95% Confidence interval, p = p value. Bold results are statistically significant to p<0.05

Linear analysis for the association between the EQ-5D-5L index and referral and discharge.

	EQ-5D-5L INDEX (N = 2429)		
Predictors	β	*95% CI*	*p*
Intercept	0.70	0.65 – 0.75	**<0.001**
Pathway stage (Ref: Referrals)			
Discharge	0.08	0.06 – 0.11	**<0.001**
Age range [years] (Ref: Under 30)			
31 – 40	-0.03	-0.08 – 0.02	0.244
41 - 50	-0.07	-0.12 – -0.02	**0.005**
51 - 60	-0.11	-0.15 – -0.06	**<0.001**
61 - 70	-0.09	-0.14 – -0.04	**<0.001**
71 and over	-0.06	-0.12 – -0.00	**0.044**
Gender (Ref: Female)			
Male	0.01	-0.01 – 0.03	0.282
Ethnicity (Ref: White)			
Other	-0.03	-0.09 – 0.02	0.241
Symptoms (Ref: No)			
Fatigue: Yes	0.04	0.01 – 0.07	**0.003**
Shortness breath: Yes	-0.03	-0.05 – -0.00	**0.042**
Chest pain: Yes	-0.03	-0.06 – -0.01	**0.008**
Heart palpitations: Yes	0.00	-0.02 – 0.03	0.915
Dizziness: Yes	-0.03	-0.06 – -0.01	**0.007**
Rashes: Yes	0.04	0.00 – 0.08	**0.026**
Diarrhoea: Yes	-0.04	-0.08 – -0.01	**0.014**
Loss appetite: Yes	-0.07	-0.10 – -0.04	**<0.001**
Cough: Yes	0.02	-0.01 – 0.04	0.147
Brain fog: Yes	-0.06	-0.08 – -0.03	**<0.001**
Sore throat: Yes	-0.03	-0.06 – 0.00	0.051
Insomnia: Yes	0.01	-0.02 – 0.03	0.540
Pins needles: Yes	-0.04	-0.07 – -0.02	**0.001**
Joint pain: Yes	-0.06	-0.09 – -0.04	**<0.001**
Depression anxiety: Yes	-0.08	-0.11 – -0.06	**<0.001**
Tinnitus: Yes	-0.03	-0.05 – 0.00	0.058
Nausea: Yes	-0.02	-0.05 – 0.02	0.311
Stomach ache: Yes	-0.03	-0.06 – 0.01	0.160

Abbreviations: 95% CI – 95% Confidence interval, p = p value.
Bold results are statistically significant to p<0.05

9.3 Appendix 3: Hypothesis test for section 5.3: Has the type of patients that are referred to the service changed over time?

Variable (categories)	Hypothesis test	statistic	P value
Gender (Male, Female)	Pearson's Chi-squared	3.12	0.21
Ethnicity (White, Other)	Pearson's Chi-squared	2.4	0.301
Hospital admission due to COVID (Yes, No)	Pearson's Chi-squared	0.34	0.987
Employment: full time (Yes, No)	Pearson's Chi-squared	15.4	**<0.001**
Employment: part time (Yes, No)	Pearson's Chi-squared	3.51	0.173
Employment: Retried (Yes, No)	Pearson's Chi-squared	4.07	0.131
Employment: Long term sick (Yes, No)	Pearson's Chi-squared	1.42	0.491
Employment: Disabled (Yes, No)	Pearson's Chi-squared	4.44	0.108
Symptom: fatigue (Yes, No)	Pearson's Chi-squared	6.61	**0.037**
Symptom: shortness breath (Yes, No)	Pearson's Chi-squared	2.41	0.299
Symptom: chest pain (Yes, No)	Pearson's Chi-squared	5.58	0.061
Symptom: heart palpitations (Yes, No)	Pearson's Chi-squared	11.88	**0.003**
Symptom: dizziness (Yes, No)	Pearson's Chi-squared	13.74	**0.001**
Symptom: rashes (Yes, No)	Pearson's Chi-squared	4.84	0.089
Symptom: diarrhoea (Yes, No)	Pearson's Chi-squared	4.77	0.092
Symptom: loss appetite (Yes, No)	Pearson's Chi-squared	9.84	**0.007**
Symptom: cough (Yes, No)	Pearson's Chi-squared	8.51	**0.014**
Symptom: brain fog (Yes, No)	Pearson's Chi-squared	23	**<0.001**
Symptom: sore throat (Yes, No)	Pearson's Chi-squared	3.42	0.181
Symptom: insomnia (Yes, No)	Pearson's Chi-squared	4.14	0.126
Symptom: pins needles (Yes, No)	Pearson's Chi-squared	3.1	0.213
Symptom: joint pain (Yes, No)	Pearson's Chi-squared	0.67	0.715
Symptom: depression anxiety (Yes, No)	Pearson's Chi-squared	14.89	**0.001**
Symptom: tinnitus (Yes, No)	Pearson's Chi-squared	2.77	0.25
Symptom: nausea (Yes, No)	Pearson's Chi-squared	1.78	0.411
Symptom: stomach ache (Yes, No)	Pearson's Chi-squared	2.72	0.256
Symptom: fever (Yes, No)	Pearson's Chi-squared	6.32	**0.042**
Symptom: headache (Yes, No)	Pearson's Chi-squared	2.21	0.332
Symptom: change taste or smell (Yes, No)	Pearson's Chi-squared	6.41	**0.041**
Symptom: other (Yes, No)	Pearson's Chi-squared	7.9	0.019
Age (Under 30, 31-40, 41-50, 51-60, 61-70, over 71)	Kruskal-Wallis	0.85	0.654
Number of days in hospital (continuous)	Kruskal-Wallis	4.66	0.097
EQ-VAS (continuous)	Kruskal-Wallis	1.07	0.587
EQ-5D-5L: Pain and discomfort	Kruskal-Wallis	3.65	0.161
EQ-5D-5L: Anxiety and depression	Kruskal-Wallis	1.97	0.373
EQ-5D-5L: Index (continuous)	Kruskal-Wallis	1.97	0.373

Due to low observation number the hypothesis test could not be undertaken on the following variables: Employment: Unemployed, Employment: looking after family, Employment: student, Employment: Other, EQ-5D-5L: mobility score, EQ-5D-5L: selfcare, EQ-5D-5L: usual actives.

9.4 Appendix 4: Hypothesis test for section 5.4: Have discharged patients' service experience changed over time?

Variable (categories)	Hypothesis test	statistic	P value
Score (Continuous)	Kruskal-Wallis	0.53	0.466
Due to low observation number the hypothesis test could not be undertaken on the following variables: being listening to, supported, involvement.			