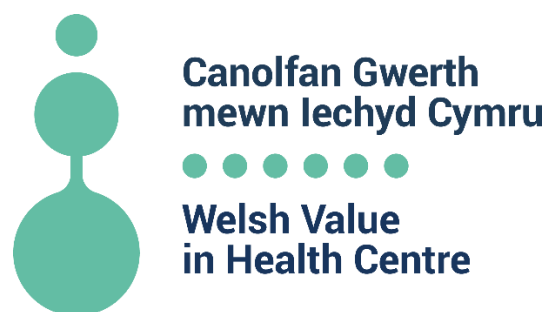# 'Adferiad' (Recovery) Long COVID Service National Evaluation
(*July 2022 update*)

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Contents

1. Summary

- This report contains the results of a cross-sectional survey administered between the 1st of September 2021 and the 31st of May 2022 to users of the various Long COVID services provided by the seven Local Health Boards (LHBs) in Wales and funded by the 'Adferiad' (Recovery) programme. The outcomes have been aggregated and analysed at a national level.

- This is the third report produced, please find the reports released previously in the year here: https://cedar.nhs.wales/our-work/evaluation/adferiad-recovery-long-covid-evaluation/

- Each LHB contributed to the survey with a different number of responders. Although data were analysed in aggregated format, the percentage of responders' contribution from each LHB to the total has been reported underneath each table and plot to give a better idea of individual contributions.

- The data collected include: responders' demographics, any COVID-19-related symptoms they experienced, the number of interactions they had with the healthcare system because of COVID-19 (primary, secondary and rehabilitation care), their general quality of life and their feedback on the interactions they had with the service.

- Responses were collected from four service user groups: 'Existing service users' (232 responders), 'New referrals' to the service (955 responders), 'Follow-up' (230 responders) and 'Discharge' (206 responders). Since the data was collected in anonymous format, it was not possible to link individuals across the four groups. Therefore, we could not evaluate the impact of the service on individual patients progressing through the service (e.g. from new referral, to follow-up, and finally to discharged).

- In all four groups: the majority were female, the most frequent age range was 51-60, most of the participants were of 'any White ethnic background' and the most frequent employment description was 'working full-time'.

- The most frequently reported symptoms following COVID-19 were 'Fatigue', 'Shortness of breath', 'Brain fog', 'Joint pain' and 'Insomnia'. Some users reported as additional symptoms 'Pain', 'Voice, mouth, throat and/or swallowing problems', various 'Mobility issues' and 'Vision and eye issues'.

- In all four service user groups, the majority of responders were not admitted to hospital due to COVID-19 (% of admitted individuals were: 24.9% for the Follow-up group; 23.9% for the 'Existing service users' group; 21% for the 'Discharge' group; 19.6% for the 'New referrals'). Of those admitted to hospital, the 'Discharge' group spent a median of 14 days in hospital, the 'Existing service users' and 'Follow-up' groups 8 days, and the 'New referrals' group 6 days.

- The 'Discharge' group had a median of 3 sessions with a general practitioner (GP) related to COVID-19, while the other groups had 4.

- The 'Follow-up' and 'Discharge' groups had a median of 5 rehabilitation sessions due to COVID-19, the 'Existing service users' group had 3 and the 'New referrals' group had 1.

- Responders' general health status was assessed using the EQ-5D-5L questionnaire. Considering the summary EQ-5D-5L index, statistical analysis revealed that those in the 'Discharge' group tended to have a higher index (i.e. better quality of life) in comparison to all other groups ('Discharge group'= 0.68; for the other groups the index ranged between 0.53-0.54). A similar result was obtained using the EQ-VAS ('Discharge group'= 65; for all other groups= 50). It is important to remind that the responses across the four groups were not linked by responder (given all data were anonymous). Therefore, it is not possible to determine whether the higher values for EQ-5D-5L and EQ-VAS for the 'Discharge' group were due to individuals' improvement or to differences in some group's characteristics in comparison to the other three groups.

- Considering the EQ-5D-5L 'Usual activities' dimension, in all groups > 8% of responders chose the most severe option (score 5) 'I am unable to do my usual activities' ('Follow-up': 13.5%; 'New referrals': 13.3%; 'Existing service users': 9.1%; 'Discharge': 8.7%). For all the remaining EQ-5D-5L dimensions ('Mobility', 'Self-care', 'Pain/discomfort' and 'Anxiety/depression'), 7% or less of responders in all groups chose the most severe option.

- We asked all service user groups (except 'New referrals') about their experiences with the Long COVID service. The highest proportion of responders in all groups reported that they '*always*' felt '*their concerns were listened to/understood*', '*supported to get the help and information they needed*' and '*involved enough in deciding what support they received*'. Using an evaluation scale from 1 to 10, more than 65% of responders rated their overall experience with the Long COVID service was above average (i.e. >5). Finally, more than 81% of responders would recommend the service.

- Considering the free text service feedback collected, the main positive themes already emerged in the previous reports were confirmed: survey responders highly appreciated the professional and emotional support provided by the Long COVID service staff and the opportunity to share their issues with other Long COVID sufferers. A few issues emerged as well, mainly related to the lack of medical testing/diagnosis/treatment, the rehabilitation not always being tailored around individuals, lack of face-to-face support, appointments at times/days of the week that are not easily accessible (e.g. during work time), slow referral/access to the service, communication issues and absence of support after discharge.

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 and change over time and can affect any system in the body.

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 1st of May 2022, the Office for National Statistics (ONS, 2022) estimated that 2.0 million people were experiencing self-reported Long COVID in the UK. Of these, 71% had their symptoms adversely affecting their day-to-day activities (19.9% reported they were "limited a lot"). The same ONS report estimated in Wales, 96,000 people with self-reported Long COVID symptoms (80% 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, 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 Welsh Local Health Boards (LHBs)[1] 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 (WG) is 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 evaluation of the Long COVID service 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 facilitating data collection from their Long COVID service users, and by providing data analysis and reporting for evaluation purposes. Two national evaluation reports have been released to WG on the 14th of January (including data up to the 31st of December 2021) and on the 30th of April 2022 (including data up to the 31st of March 2022) These reports have been published on Cedar's website (https://cedar.nhs.wales/our-work/evaluation/adferiad-recovery-long-covid-evaluation/).

The purpose of the current report update is to enable a better understanding of the value of the Long COVID service in Wales, by adding more recent data to the analysis (with data collected up to the 31st of May 2022).

As with the previous two publications, this report contains the analysis and summary of patient-reported outcome and experience measures (PROMs and PREMs) collected at a national level via a cross-sectional survey (Sections 3.1 and 4). Data were collected from four groups of Long COVID service users in Wales, with the final aim to describe and compare their health status and feedback on the recovery services available to them. Table 1 presents the definitions of the four service user groups.

Service user group	Definition
Existing service users	Those within the Long COVID service on the 1st of September 2021 (collection of data from this group was concluded on the 2nd of March 2022)
New referrals	New referrals post 1st September 2021.
Follow-up	Service users three months from the date of referral who have not yet been discharged
Discharge	Those discharged from the Long COVID service between the 6th of September 2021 and the 31st of May 2022

Table 1. Definitions of the four service user groups used in the report

In order to provide further context, information collected from each LHB about demand for their Long COVID service is also presented at the end of this report (Sections 3.2 and 5).

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[1] Aneurin Bevan University Health Board (AB UHB), Betsi Cadwaladr University Health Board (BC UHB), Cardiff and Vale University Health Board (C&V UHB), Cwm Taf Morgannwg University Health Board (CTM UHB), Hywel Dda University Health Board (HD UHB), Powys Teaching Health Board (PT HB) and Swansea Bay University Health Board (SB UHB)

3. Methods

3.1 National service user questionnaire data collection

The data were collected from the 1st of September 2021 to the 31st of May 2022 via secure web questionnaires set up by Cedar and administered by the LHBs to their Long COVID service users. Each LHB received the same set of questionnaires. All questionnaires were designed using the Online Surveys web tool (https://www.onlinesurveys.ac.uk/), which allows licenced users to build web pages that collect answers in an anonymous format. A Welsh version of each questionnaire was also available for those who requested it. AB UHB and HD UHB opted not to use the Online Survey system provided by Cedar, and collected data via an alternative data platform (DrDoctor). They provided their data to Cedar at the end of the collection period.

A combination of closed and open-ended questions was agreed with the Directors of Therapies of the LHBs to investigate the health status of Long COVID service users, along with their interaction with the service. The questionnaire is available in Appendix 1.

Table 2 shows the main sections of the questionnaire. Note that the 'About your experience' section was not included in the 'New referrals' group's questionnaire.

Questionnaire section	Questions	Description	Administered to
Your Long COVID support	Question 0 (Q0)	Service users were explicitly asked to indicate which LHB they were referred to for accessing the Long COVID service. This extra question was added to the rest of the original survey questionnaire (Q1-Q21) 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'

Table 2. Survey questionnaire sections

Due to the short time frames involved in starting the data collection, it was not possible to request identifiable data because of information governance constraints. As the questionnaire responses were anonymous, data could not be linked across the four service user groups. Therefore, it was not possible to establish whether some responders might have been included in more than one group (for example, if the same individual answered a questionnaire at multiple time points, being first a 'new referral' and then being 'discharged' from the service). Instead, each group was considered as an independent cross-section in all the analyses.

In addition to the survey questionnaires administered directly by the LHBs to their service users, we also collected responses via a link posted on Cedar social media account (Twitter) on the 22nd of March 2022. This additional survey questionnaire contained the same questions as the main survey (Q0-Q21)

and two additional questions (Q22 and Q23, see Appendix 2) to identify the service user group of the responder.

It is important to note that each LHB had a different number of responders. Although data were analysed in aggregated format, the percentage of responders' contribution from each LHB to the total has been reported underneath each table and plot to give a better idea of individual contributions.

3.1.1 EQ-5D (EuroQol-5 Dimension) questionnaire

Q9-Q14 represent the EQ-5D-5L questionnaire (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) to describe their quality of life in each dimension. These levels were then converted into numeric scores from 1 (= best health possible) to 5 (= worst health possible).

The five scores can be summarised as a unique index of general health (the EQ-5D-5L index), using a validated look-up table with mapping retrieved from research literature and specific for the UK population (Van Hout et al., 2012). The EQ-5D-5L index ranges from values <0 ('worse than dead') to 1 ('full health'), with an anchor at 0 for 'dead'.

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

3.1.2 Analysis of quantitative data

The responses from close-ended questions (i.e. excluding Q6a, Q19 and Q20) were summarised as counts, percentages, medians and interquartile ranges. All percentages and statistics were separately calculated for each service user group reported in Table 1.

Normality of distributions for the EQ-5D index and EQ-VAS score was assessed using the Shapiro-Wilk test. Since the distributions were not normal, their differences across service user groups were tested using the Kruskal-Wallis H test (both the H statistic and the p-value are reported). 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. The statistical significance level was set at $p < 0.05$.

Statistical analyses were carried out using R statistical software (version 4.1.1) and RStudio integrated development environment (version 2021.09.0).

3.1.3 Analysis of qualitative data

For the analysis of free text data (responses to Q6a, Q19 and Q20), recurrent themes were identified, extracted and summarised. Themes were identified by two of the authors and counts of themes per service user group were calculated using Excel and R software.

For the two 'Long COVID service experience' open questions (Q19 and Q20), free text answers were analysed in parallel, since some responders provided their feedback without strictly matching the polarity of the question (i.e., Q19 contained some negative feedback and Q20 some positive feedback, although the opposite was expected). The final themes extracted were classified as 'Positive feedback', 'Negative feedback' or 'Suggestions for improvement'.

In this updated report, only new free text responses to Q19 and Q20 were analysed (i.e. those collected between the 1st of April 2022 and the 31st of May 2022). The aim was to identify any new emerging themes and confirm recurrent ones. The previous report releases contain other themes previously identified in the data collected from the 1st of September 2021 to the 31st of March 2022 https://cedar.nhs.wales/our-work/evaluation/adferiad-recovery-long-covid-evaluation/.

3.1.4 Assignment of survey responses to a specific LHB

For responses collected between the 1st of September 2021 to the 25th of January 2022, assignment of each response to a specific LHB was carried out on the basis of the specific questionnaire web link used to collect the response (each LHB was assigned distinct web survey links to administer to each of their Long COVID service user groups). One problem with this methodology was that in the free text answers some responders declared to have accessed the service in one LHB although they were responding via a link corresponding to another LHB. To try to control this mismatch, we added an extra question (Q0) in the survey questionnaires from the 26th of January 2022 onwards, asking to responders directly from which LHB they accessed the service. The answer provided by each responder in Q0 (rather than the origin of the survey link they answered) was then used as reference to match them to a specific LHB.

3.1.5 Data filtering

Some responses were excluded from the main analysis (Sections 4.1-4.7) and classified as 'additional responses' as detailed below:

- On the 5th of November and on the 9th of December a link to the Cardiff & Vale 'Existing service users' questionnaire was published on Twitter by a member of the public on their personal account. This gave questionnaire access to those who may not have been representative of any of the service user groups. The Twitter publication was associated to a peak in responses, many of which were identifiable through free text answers given as not being from appropriate service users. Therefore, all responses were excluded for the days identified unless the response clearly mentioned in the free text answers that they were Long COVID service users.

- Responses from any date were excluded if in the free text answers (Q19 and Q20) or in Q0 responders explicitly declared that they did not access the Long COVID service. The reasons for these responses are unclear, however one example might be those individuals referred to the service who might have been provided with a questionnaire link before they actually accessed the service.

- Responses collected via the official link on social media were excluded if the responders declared '*I have not been referred*' or '*I am waiting to receive my first appointment/support from the Long COVID Service*' to either Q22 or Q23 (i.e. they were classified as 'additional responders', see Appendix 2).

These 'additional responses' were separately analysed (Section 4.8) for demographics (Q1-Q4), COVID-related symptoms (Q6 and Q6a) and free text comments (Q19 and Q20). As the questionnaires specifically stated that this data gathering exercise encompassed Wales, it was assumed that these 'additional' responders would be Long COVID sufferers registered with GPs in NHS Wales. Therefore, this analysis is also reported, to provide some feedback from people who had not had access to Long COVID services.

3.2 Local Health Boards (LHBs) demand data collection

Additional data was collected from each LHB via a questionnaire to quantify the demand for the service provided. Since this data was heterogenous (i.e. different LHBs have structured their Long COVID service differently and started it at different times), it was not possible to summarise this information on a national level. Data provided by all LHBs was reported in tabular format using counts (Section 5).

4. Results of Long COVID Service National Survey

The survey collected 1826 responses, from the 1st September 2021 to the 31st of May 2022. 1786 (97.8%) of them were responses from responders who accessed the survey using the email link provided by their LHB. The remaining 40 (2.2%) were collected from responders who accessed the survey via an official link shared on Cedar's social media Twitter account.

From the total, 1623 responses (88.9%) were included in the main analysis of Long COVID service users (Sections 4.1-4.7). The remaining 203 responses (11.1%) were analysed separately as 'additional responses' from individuals who did not access the service (Section 4.8).

Only 6 responders declared they were referred to the Long COVID service of an LHB not matching the survey questionnaire link (see Section 3.1.4) (3 responses for the AB UHB service, provided via C&V UHB link; one response for C&V UHB service provided via AB UHB link; one response for AB UHB service provided via SB UHB link; one response for PT HB service provided via SB UHB link).

4.1 Demographics of responders (Q1-Q4)

Table 3 shows total sample sizes (i.e. total responders) and summary demographics of the four service user groups. Ethnicities are reported in Figure 1 and Figure 2, while responders' employment status in Figure 3.

The largest group was 'New referrals' (n=955), while the 'Follow-up' group was the smallest (n=206). The largest number of responders of the 'Existing service users' group were from C&V UHB (33.6%), for 'New referrals' and 'Discharge' they were from CTM UHB (31% and 66%, respectively), while for 'Follow-up' they were from HD UHB (25.2%). In all four service user groups: the majority were female, the most frequent age range was 51-60, most of the responders were of '*Any White background*' and the most frequent employment status was '*Full-time employed/self-employed*'.

		Existing service users	New referrals	Follow-up	Discharge	Totals
Number of responders		232 (100%)	955 (100%)	230 (100%)	206 (100%)	**1623 (100%)**
Health Board	**AB UHB**	22 (9.5%)	89 (9.3%)	50 (21.7%)	0 (0%)	**161 (9.92%)**
	BC UHB	0 (0%)	183 (19.2%)	23 (10%)	1 (0.5%)	**207 (12.75%)**
	C&V UHB	**78 (33.6%)**	152 (15.9%)	39 (17%)	18 (8.7%)	**287 (17.68%)**
	CTM UHB	77 (33.2%)	**296 (31%)**	33 (14.3%)	**136 (66%)**	**542 (33.39%)**
	HD UHB	0 (0%)	126 (13.2%)	**58 (25.2%)**	12 (5.8%)	**196 (12.08%)**
	PT HB	16 (6.9%)	10 (1%)	5 (2.2%)	4 (1.9%)	**35 (2.16%)**
	SB UHB	39 (16.8%)	99 (10.4%)	22 (9.6%)	35 (17%)	**195 (12.01%)**
Gender	**Female**	**169 (72.8%)**	**667 (69.8%)**	**151 (65.7%)**	**121 (58.7%)**	**1108 (68.27%)**
	Male	63 (27.2%)	285 (29.8%)	79 (34.3%)	85 (41.3%)	**512 (31.55%)**
	Non-Binary	0 (0%)	1 (0.1%)	0 (0%)	0 (0%)	**1 (0.06%)**
	Prefer not to say	0 (0%)	2 (0.2%)	0 (0%)	0 (0%)	**2 (0.12%)**
Age range	**17 and under**	0 (0%)	0 (0%)	0 (0%)	0 (0%)	**0 (0%)**
	18 - 30	17 (7.3%)	57 (6%)	6 (2.6%)	11 (5.3%)	**91 (5.61%)**
	31 - 40	26 (11.2%)	158 (16.5%)	35 (15.2%)	19 (9.2%)	**238 (14.66%)**
	41 - 50	64 (27.6%)	242 (25.3%)	68 (29.6%)	56 (27.2%)	**430 (26.49%)**
	51 - 60	**77 (33.2%)**	**306 (32%)**	**73 (31.7%)**	**69 (33.5%)**	**525 (32.35%)**
	61 - 70	40 (17.2%)	147 (15.4%)	39 (17%)	38 (18.4%)	**264 (16.27%)**
	71 - 80	7 (3%)	42 (4.4%)	9 (3.9%)	13 (6.3%)	**71 (4.37%)**
	81 - 90	1 (0.4%)	3 (0.3%)	0 (0%)	0 (0%)	**4 (0.25%)**
	91 and over	0 (0%)	0 (0%)	0 (0%)	0 (0%)	**0 (0%)**
Language used to respond	**English**	231 (99.6%)	953 (99.8%)	228 (99.1%)	205 (99.5%)	**1617 (99.63%)**
	Welsh	1 (0.4%)	2 (0.2%)	2 (0.9%)	1 (0.5%)	**6 (0.37%)**

Table 3. Demographics of survey responders. Figures represent counts and percentages for each service user group

Existing service users
N responders = 232 (100% of total group responders)

Ethnicity	Count
Any White background	224(96.6%)
White and Black Caribbean	1(0.4%)
Any other mixed background/ multiple ethnic background	1(0.4%)
Pakistani	1(0.4%)
Bangladeshi	1(0.4%)
Any other Asian background	1(0.4%)
African	1(0.4%)
Any other ethnic group	1(0.4%)
Prefer not to say	1(0.4%)
Gypsy or Irish Traveller	0(0%)
White and Black African	0(0%)
White and Asian	0(0%)
Indian	0(0%)
Chinese	0(0%)
Caribbean	0(0%)
Any other Black background	0(0%)
Arab	0(0%)

Follow-up
N responders = 230 (100% of total group responders)

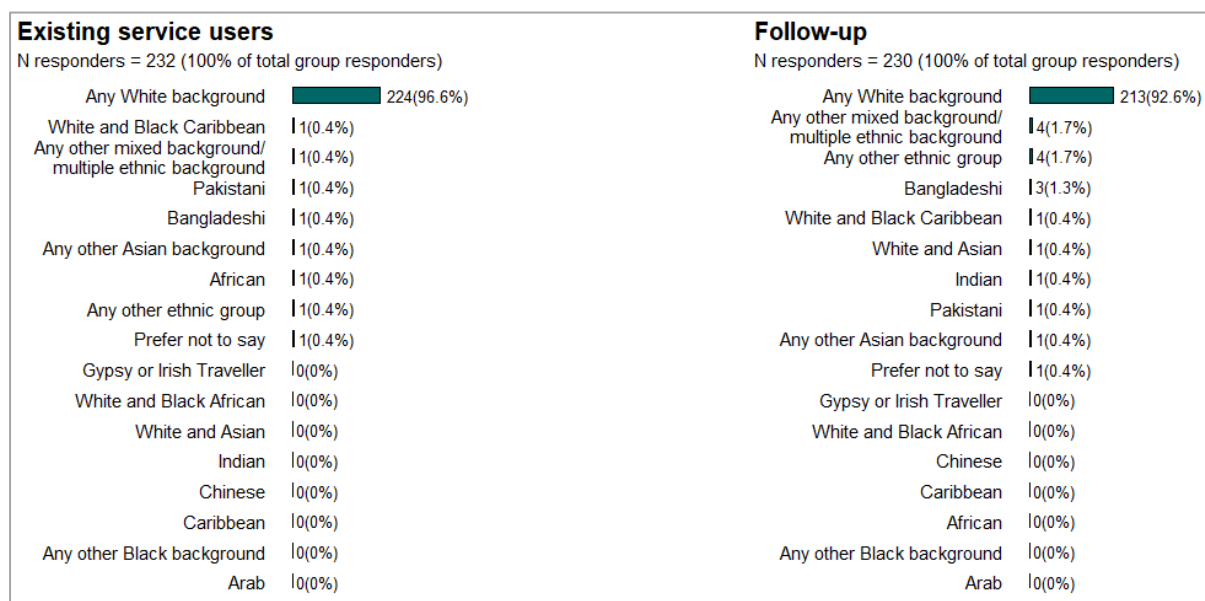| Ethnicity	Count
Any White background	213(92.6%)
Any other mixed background/ multiple ethnic background	4(1.7%)
Any other ethnic group	4(1.7%)
Bangladeshi	3(1.3%)
White and Black Caribbean	1(0.4%)
White and Asian	1(0.4%)
Indian	1(0.4%)
Pakistani	1(0.4%)
Any other Asian background	1(0.4%)
Prefer not to say	1(0.4%)
Gypsy or Irish Traveller	0(0%)
White and Black African	0(0%)
Chinese	0(0%)
Caribbean	0(0%)
African	0(0%)
Any other Black background	0(0%)
Arab	0(0%)

Figure 1. Bar plots for: [Q3] "Please tell us your ethnicity". Data for 'Existing service users' and 'Follow-up' groups. The numbers at the end of each bar indicate number of responders and percentage for each answer option within each group. (% of responses by LHB - AB UHB: 9.9%; BC UHB: 12.8%; CAV UHB: 17.7%; CTM UHB: 33.4%; HD UHB: 12.1%; PT HB: 2.2%; SB UHB: 12%)

New referrals
N responders = 955 (100% of total group responders)

Ethnicity	Count
Any White background	921(96.4%)
White and Asian	6(0.6%)
Any other mixed background/ multiple ethnic background	5(0.5%)
Any other Asian background	5(0.5%)
Prefer not to say	5(0.5%)
Indian	4(0.4%)
Any other ethnic group	3(0.3%)
White and Black African	2(0.2%)
White and Black Caribbean	1(0.1%)
Pakistani	1(0.1%)
Chinese	1(0.1%)
African	1(0.1%)
Gypsy or Irish Traveller	0(0%)
Bangladeshi	0(0%)
Caribbean	0(0%)
Any other Black background	0(0%)
Arab	0(0%)

Discharge
N responders = 206 (100% of total group responders)

Ethnicity	Count
Any White background	199(96.6%)
White and Asian	3(1.5%)
Any other mixed background/ multiple ethnic background	2(1%)
Prefer not to say	2(1%)
Gypsy or Irish Traveller	0(0%)
White and Black Caribbean	0(0%)
White and Black African	0(0%)
Indian	0(0%)
Pakistani	0(0%)
Bangladeshi	0(0%)
Chinese	0(0%)
Any other Asian background	0(0%)
Caribbean	0(0%)
African	0(0%)
Any other Black background	0(0%)
Arab	0(0%)
Any other ethnic group	0(0%)

Figure 2. Bar plots for: [Q3] "Please tell us your ethnicity". Data for 'New referrals' and 'Discharge' groups. The numbers at the end of each bar indicate number of responders and percentage for each answer option within each group. (% of responses by LHB - AB UHB: 9.9%; BC UHB: 12.8%; CAV UHB: 17.7%; CTM UHB: 33.4%; HD UHB: 12.1%; PT HB: 2.2%; SB UHB: 12%)
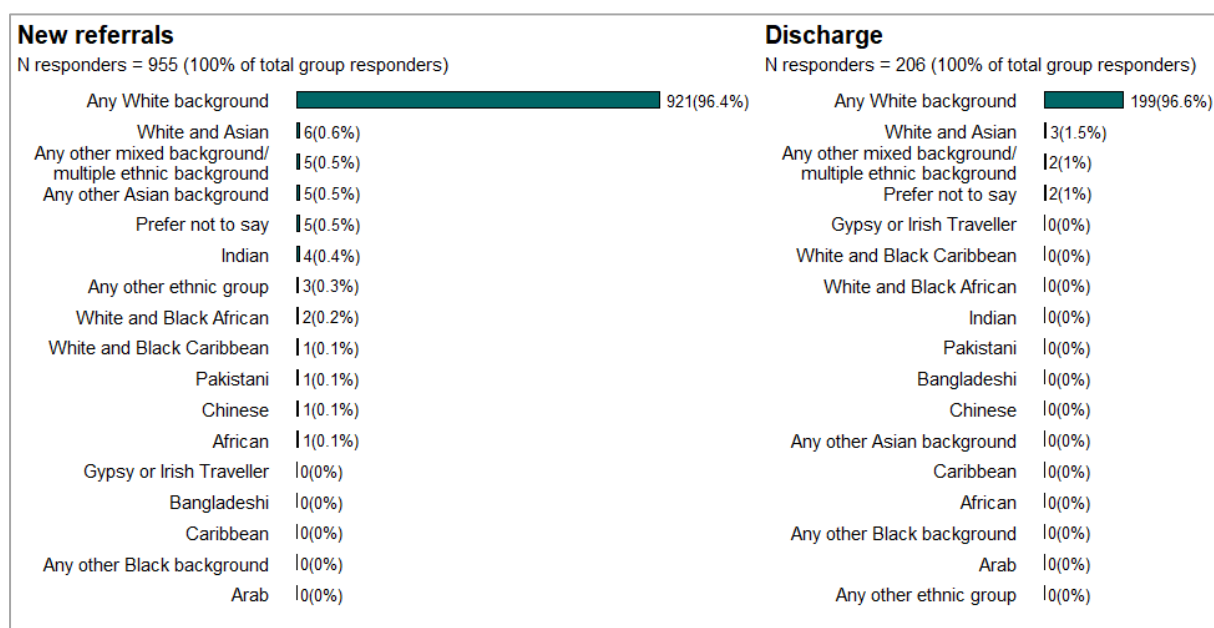
Existing service users
N responders = 231 (99.6% of total group responders)

Full-time employed or self-employed	121(52.4%)
Long-term sick	46(19.9%)
Part-time employed or self-employed	36(15.6%)
Retired	27(11.7%)
Disabled	10(4.3%)
Student	4(1.7%)
Unemployed / seeking work	2(0.9%)
Looking after home or family	2(0.9%)
Other	2(0.9%)

Follow-up
N responders = 230 (100% of total group responders)

Full-time employed or self-employed	98(42.6%)
Long-term sick	52(22.6%)
Part-time employed or self-employed	41(17.8%)
Retired	25(10.9%)
Disabled	12(5.2%)
Other	7(3%)
Unemployed / seeking work	3(1.3%)
Looking after home or family	2(0.9%)
Student	2(0.9%)

New referrals
N responders = 950 (99.5% of total group responders)

Full-time employed or self-employed	453(47.7%)
Part-time employed or self-employed	204(21.5%)
Long-term sick	185(19.5%)
Retired	101(10.6%)
Disabled	23(2.4%)
Unemployed / seeking work	20(2.1%)
Looking after home or family	15(1.6%)
Student	14(1.5%)
Other	14(1.5%)

Discharge
N responders = 203 (98.5% of total group responders)

Full-time employed or self-employed	95(46.8%)
Long-term sick	42(20.7%)
Retired	34(16.7%)
Part-time employed or self-employed	30(14.8%)
Disabled	9(4.4%)
Student	2(1%)
Unemployed / seeking work	1(0.5%)
Looking after home or family	1(0.5%)
Other	1(0.5%)

Figure 3. Bar plots for: [Q4] *"Which of these definitions describe your employment status?"* Multiple responses per participant were allowed for this question (i.e., for each bar, 100% would represent all responders within the group chose that option). (% of responses by LHB - AB UHB: 10%; BC UHB: 12.8%; CAV UHB: 17.8%; CTM UHB: 33.2%; HD UHB: 12%; PT HB: 2.2%; SB UHB: 12.1%)

4.2 Hospital admissions due to COVID-19 and length of stay (Q5)

The majority of responders accessing the Long COVID service were not admitted to hospital because of COVID-19 (green areas in Figure 4). The 'Follow-up' group had the highest percentage of admitted (red areas) service users (24.9%), closely followed by the 'Existing service users' group (23.9%) the 'Discharge' group (21%) and the 'New referrals' group (19.6%).
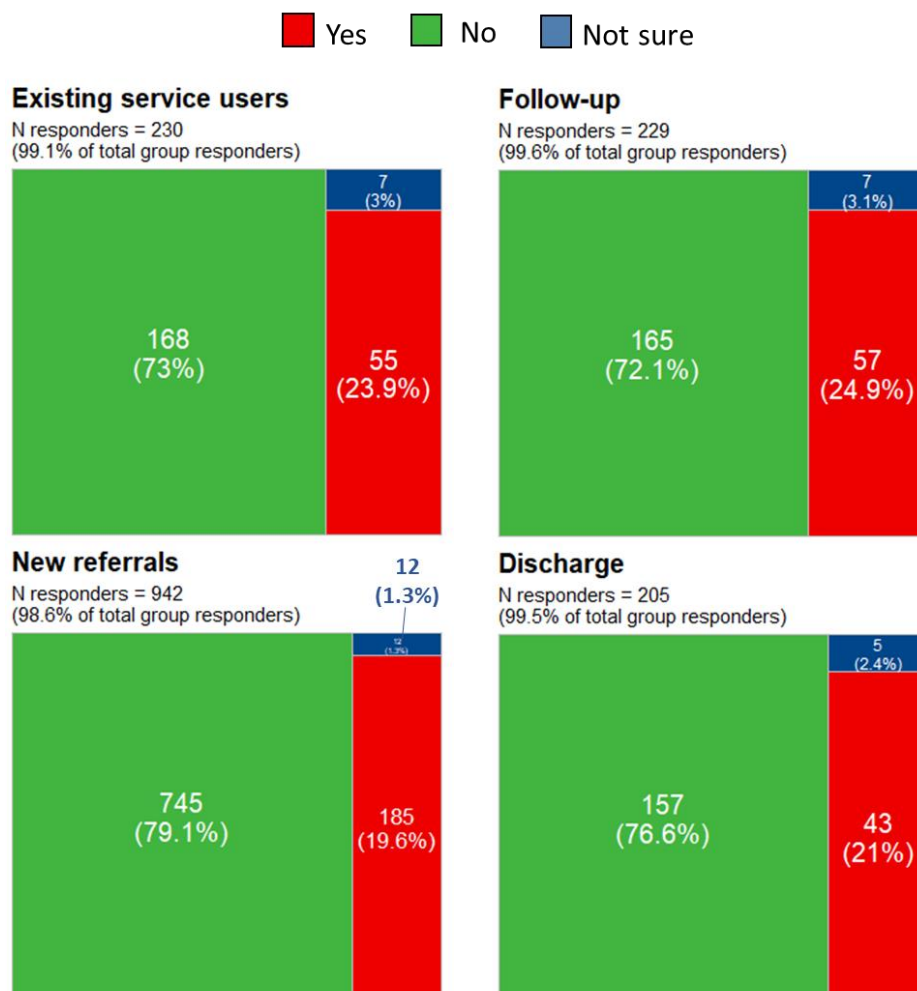

Figure 4. Tree map plots for: [Q5] **"*Have you been admitted to hospital as an in-patient as a result of COVID-19?"*** The numbers in the coloured areas indicate number of responders and percentage for each answer option within each service user group. (% of responses by LHB - AB UHB: 10%; BC UHB: 12.4%; CAV UHB: 17.7%; CTM UHB: 33.4%; HD UHB: 12.2%; PT HB: 2.2%; SB UHB: 12.1%)

Responders who were hospitalised because of COVID-19 were further asked how many days they spent in hospital. For each service user group, summary statistics and distribution plots are reported in Table 4 and Figure 5. The 'Discharge' group spent a median of 14 days in hospital, the 'Existing service users' and 'Follow-up' groups 8 days, and the 'New referrals' group 6 days.

	Existing service users	New referrals	Follow-up	Discharge
Number of responders	54	164	45	36
% who answered the question	23.3%	17.2%	19.6%	17.5%
Minimum value	0	0	1	1
Median (IQR)	8 (5,21)	6 (2,14)	8 (3,21)	14 (5.8,46.5)
Maximum value	95	182	150	190

**Table 4. Summary statistics for [Q5a]: "*(If you answered 'Yes' to Q5) In total, how many days did you spend in hospital because of COVID-19? (If you are still in hospital, please tell us how many days you have been in hospital so far)".* IQR = Inter-Quartile Range. (% of responses by LHB - AB UHB: 4%; BC UHB: 13%; CAV UHB: 18.1%; CTM UHB: 33.8%; HD UHB: 16.1%; PT HB: 1.3%; SB UHB: 13.7%)

Figure 5. Box plots for [Q5a]: *(If you answered 'Yes' to Q5) In total, how many days did you spend in hospital because of COVID-19? (If you are still in hospital, please tell us how many days you have been in hospital so far).* For each service user group, number of responders (N) and the % of total group responders are reported under the group label. (% of responses by LHB - AB UHB: 4%; BC UHB: 13%; CAV UHB: 18.1%; CTM UHB: 33.8%; HD UHB: 16.1%; PT HB: 1.3%; SB UHB: 13.7%)

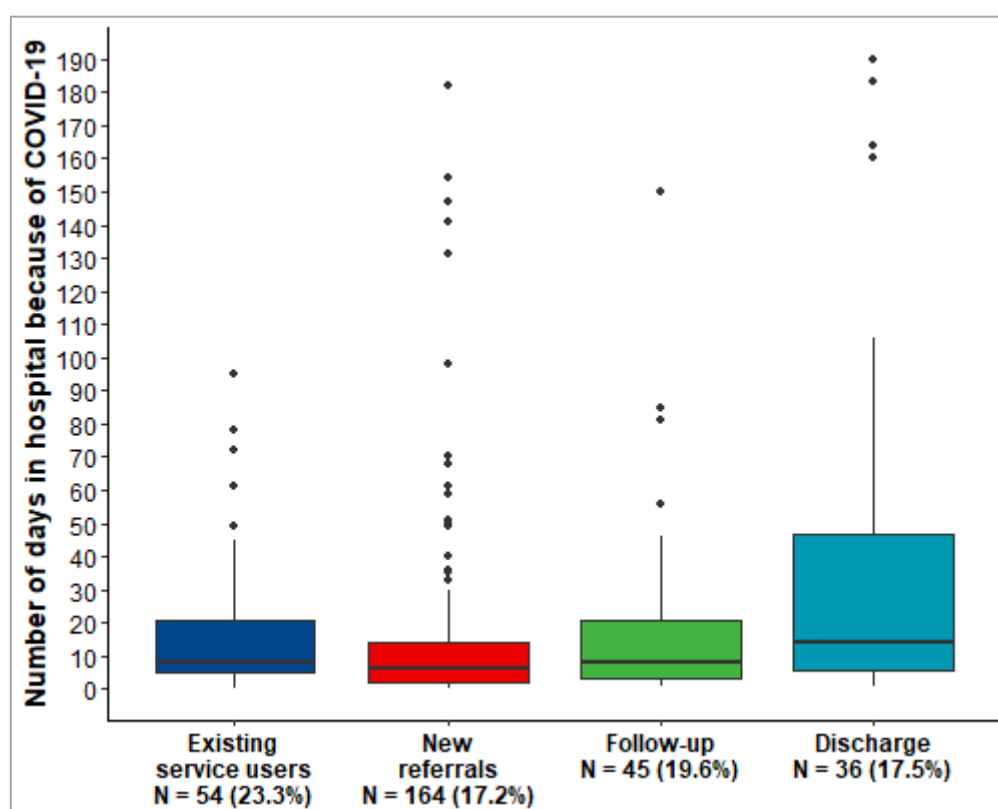## 4.3 Long COVID symptoms (Q6)

When asked about their Long COVID symptoms, participants chose from 21 possible options (Figure 6 and Figure 7) which had been identified as symptoms from the NHS Long COVID website (https://www.nhs.uk/conditions/coronavirus-covid-19/long-term-effects-of-coronavirus-long-covid/). *'Fatigue'* was the most commonly selected symptom by all groups ('Existing service users': 91.4%, 'New referrals': 81.7%, 'Discharge': 71.4% and 'Follow-up': 69.6%). Other frequent symptoms (experienced by more than 50% of responders) were *'Shortness of breath'*, *'Brain fog'*, *'Joint pain'* and *'Insomnia'*.

Existing service users
N responders = 232 (100% of total group responders)

Symptom	Value
Extreme tiredness (fatigue)	212(91.4%)
Problems with memory and concentration ('brain fog')	181(78%)
Shortness of breath	166(71.6%)
Joint pain	143(61.6%)
Difficulty sleeping (insomnia)	138(59.5%)
Depression and anxiety	115(49.6%)
Headache	110(47.4%)
Chest pain or tightness	105(45.3%)
Dizziness	105(45.3%)
Heart palpitations	100(43.1%)
Cough	93(40.1%)
Pins and needles	90(38.8%)
Changes to sense of taste or smell	84(36.2%)
Tinnitus or earache	65(28%)
Loss of appetite	63(27.2%)
Sore throat	62(26.7%)
Diarrhoea	57(24.6%)
Feeling sick (nausea)	55(23.7%)
Stomach ache	43(18.5%)
A high temperature (fever)	41(17.7%)
Other	37(15.9%)
Rashes	29(12.5%)

Follow-up
N responders = 230 (100% of total group responders)

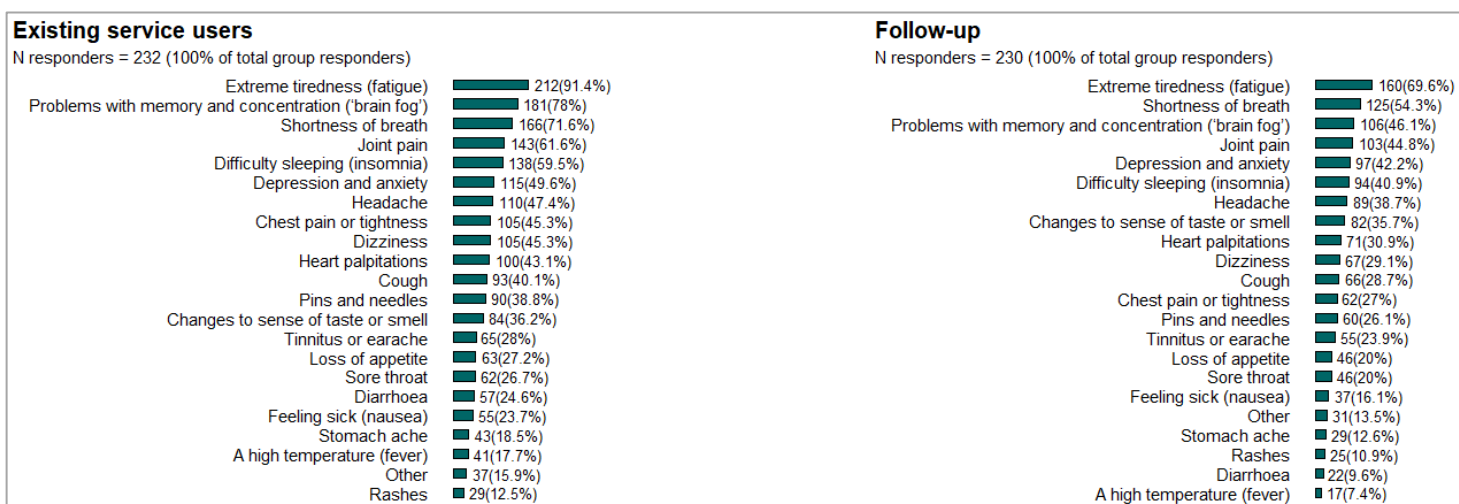| Symptom	Value
Extreme tiredness (fatigue)	160(69.6%)
Shortness of breath	125(54.3%)
Problems with memory and concentration ('brain fog')	106(46.1%)
Joint pain	103(44.8%)
Depression and anxiety	97(42.2%)
Difficulty sleeping (insomnia)	94(40.9%)
Headache	89(38.7%)
Changes to sense of taste or smell	82(35.7%)
Heart palpitations	71(30.9%)
Dizziness	67(29.1%)
Cough	66(28.7%)
Chest pain or tightness	62(27%)
Pins and needles	60(26.1%)
Tinnitus or earache	55(23.9%)
Loss of appetite	46(20%)
Sore throat	46(20%)
Feeling sick (nausea)	37(16.1%)
Other	31(13.5%)
Stomach ache	29(12.6%)
Rashes	25(10.9%)
Diarrhoea	22(9.6%)
A high temperature (fever)	17(7.4%)

Figure 6. Bar plots for [Q6]: *"Please tell us about any symptoms you have experienced today due to COVID-19"*. Data for 'Existing service users' and 'Follow-up' groups. Multiple responses per participant were allowed for this question (i.e., for each bar, 100% would represent that all responders within the group chose that option). (% of responses by LHB - AB UHB: 9.9%; BC UHB: 12.8%; CAV UHB: 17.7%; CTM UHB: 33.4%; HD UHB: 12%; PT HB: 2.2%; SB UHB: 12%)
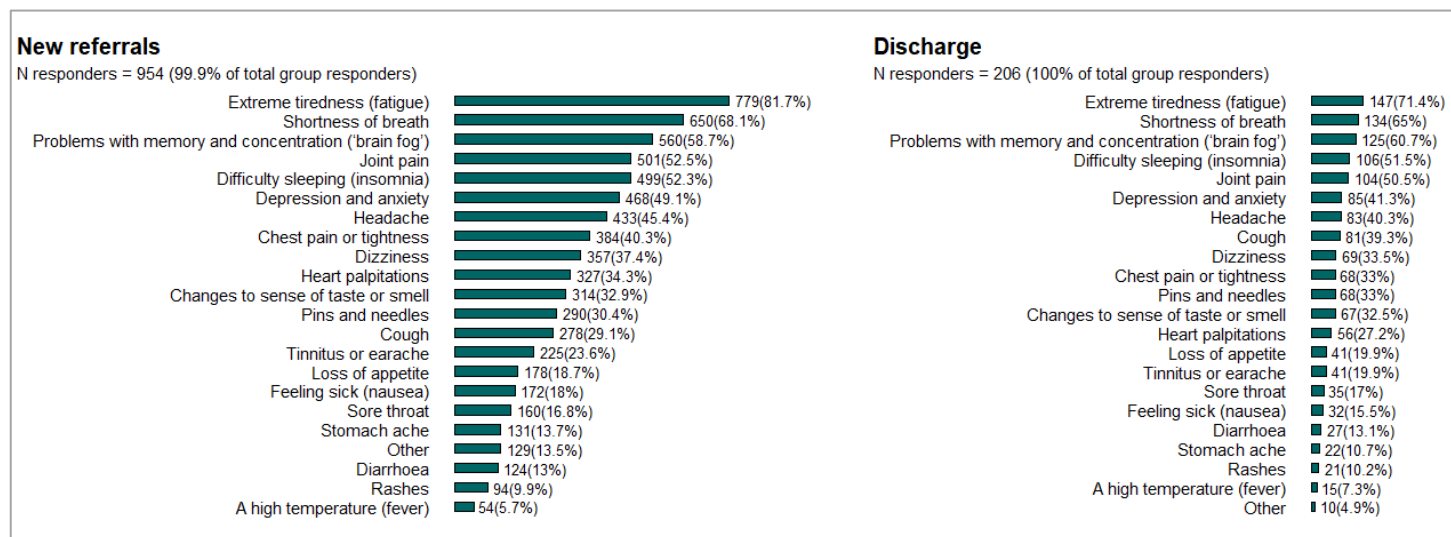
New referrals
N responders = 954 (99.9% of total group responders)

Symptom	Value
Extreme tiredness (fatigue)	779(81.7%)
Shortness of breath	650(68.1%)
Problems with memory and concentration ('brain fog')	560(58.7%)
Joint pain	501(52.5%)
Difficulty sleeping (insomnia)	499(52.3%)
Depression and anxiety	468(49.1%)
Headache	433(45.4%)
Chest pain or tightness	384(40.3%)
Dizziness	357(37.4%)
Heart palpitations	327(34.3%)
Changes to sense of taste or smell	314(32.9%)
Pins and needles	290(30.4%)
Cough	278(29.1%)
Tinnitus or earache	225(23.6%)
Loss of appetite	178(18.7%)
Feeling sick (nausea)	172(18%)
Sore throat	160(16.8%)
Stomach ache	131(13.7%)
Other	129(13.5%)
Diarrhoea	124(13%)
Rashes	94(9.9%)
A high temperature (fever)	54(5.7%)

Discharge
N responders = 206 (100% of total group responders)

Symptom	Value
Extreme tiredness (fatigue)	147(71.4%)
Shortness of breath	134(65%)
Problems with memory and concentration ('brain fog')	125(60.7%)
Difficulty sleeping (insomnia)	106(51.5%)
Joint pain	104(50.5%)
Depression and anxiety	85(41.3%)
Headache	83(40.3%)
Cough	81(39.3%)
Dizziness	69(33.5%)
Chest pain or tightness	68(33%)
Pins and needles	68(33%)
Changes to sense of taste or smell	67(32.5%)
Heart palpitations	56(27.2%)
Loss of appetite	41(19.9%)
Tinnitus or earache	41(19.9%)
Sore throat	35(17%)
Feeling sick (nausea)	32(15.5%)
Diarrhoea	27(13.1%)
Stomach ache	22(10.7%)
Rashes	21(10.2%)
A high temperature (fever)	15(7.3%)
Other	10(4.9%)

Figure 7. Bar plots for [Q6]: *"Please tell us about any symptoms you have experienced today due to COVID-19"*. Data for 'New referrals' and 'Discharge' groups. Multiple responses per participant were allowed for this question (i.e., for each bar, 100% would represent that all responders within the group chose that option). (% of responses by LHB - AB UHB: 9.9%; BC UHB: 12.8%; CAV UHB: 17.7%; CTM UHB: 33.4%; HD UHB: 12%; PT HB: 2.2%; SB UHB: 12%)

Responders were also able to add 'other symptoms' which were not on the list via a free text option. 'Other' Long COVID symptoms not included in the questionnaire (reported by 176 responders) are summarised in Table 5. Service users most often mentioned *'Pain'* of various nature (e.g. muscle pain and general somatic pain, as well as localised in specific areas), problems with their *'Voice, mouth, throat and/or swallowing'*, *'Mobility issues'* (often due to leg issues) and various *'Vision and eye issues'*.

OTHER SYMPTOMS	Existing service users N = 37 (15.9%)	New referrals N = 107 (11.2%)	Follow-up N = 22 (9.7%)	Discharge N = 10 (4.9%)
Pain (e.g muscle pain/stiffness, general or localised pain in the body)	8	30	5	2
Voice, mouth, throat and swallow issues	3	16	8	2
Mobility issues (including leg issues, balance issues, muscle weakness)	6	15	1	3
Vision and eye issues	8	8	3	1
Excessive sweating/feeling hot and/or inability to regulate body temperature	3	10	1	1
Bladder issues (e.g. inflammation and incontinence)	1	6	2	1
Issues with limb extremities (cold, sore, itching, swelling)	2	6	1	0
Hair loss	4	5	0	0
Nose and/or sinus issues (e.g. nose bleed, nasal inflammation, sinus congestion)	2	3	2	0
Hypersensitivity (e.g. to light, sound, pain or skin hypersensitivity)	2	3	1	0
Cardiovascular issues (e.g. tachycardia)	3	2	0	0
Gastrointestinal issues	1	3	1	0
Involuntary tremor	0	5	0	0
Reflux, heartburn	2	3	0	0
Speech production or understanding issues	1	2	2	0
Hearing loss	1	1	0	2
Neurological pain and pins and needles	0	3	1	0
Post-exertional malaise	0	2	2	0
Deconditioning	0	3	0	0
Dysautonomia issues/Postural Orthostatic Tachycardia Syndrome (POTS)/ Orthostatic Intolerance	0	2	1	0
Hypertension	0	2	1	0
Numbness of body (e.g. feet, face)	2	1	0	0
Weight issue, either gain or loss	0	2	0	1
Falling	1	0	1	0
Constant muscle fasciculations	0	1	1	0
Swollen glands	0	1	1	0
Hyperventilating as a result of exposure to fresh air/ Bronchial hyperactivity	0	1	1	0
Lower immunity (e.g. increase rate of chest infections)	1	1	0	0
Lung issues	0	2	0	0
Menstrual issues	1	1	0	0

Panic attacks	0	2	0	0
Phlegm at night	1	1	0	0
Vivid dreams, nightmares, waking up sharp with anxiety	0	2	0	0
Vertigo	1	0	1	0
Allergy, MCAS (Mast Cell Activation Syndrome)	0	0	0	1
Arthritis	0	0	1	0
Hiatus hernia	0	1	0	0
Inflammation	0	1	0	0
Itchiness	0	0	1	0
Mood issues (e.g. extreme mood swings, low mood)	0	1	0	0
Post-Traumatic Stress Disorder	0	1	0	0
Shingles	1	0	0	0
Excessive thirst	1	0	0	0

Table 5. **Other symptoms due to Long COVID not listed in the questionnaire.** N = number of responders per service user group.

4.4 Access to General Practitioner (GP) care due to COVID-19 (Q7)

Responders were asked how many times they accessed GP care in the last 6 months because of COVID-19. Summary statistics and distribution plots are reported in Table 6 and Figure 8. The 'Discharge' group had a median of 3 GP sessions, while the other groups had 4.

	Existing service users	New referrals	Follow-up	Discharge
Number of responders	225	853	173	191
% who answered the question	97%	89.3%	75.2%	92.7%
Minimum value	0	0	0	0
Median (IQR)	4 (2,6)	4 (2,6)	4 (2,6)	3 (1,5)
Maximum value	20	100	30	20

Table 6. Summary statistics for [Q7]: *"How many GP visits/contacts (face-to-face or remotely) have you had in the last 6 months related to COVID-19?"* IQR = Inter-Quartile Range. (% of responses by LHB - AB UHB: 3.1%; BC UHB: 13.5%; CAV UHB: 18.9%; CTM UHB: 36.7%; HD UHB: 12.7%; PT HB: 2.4%; SB UHB: 12.9%).
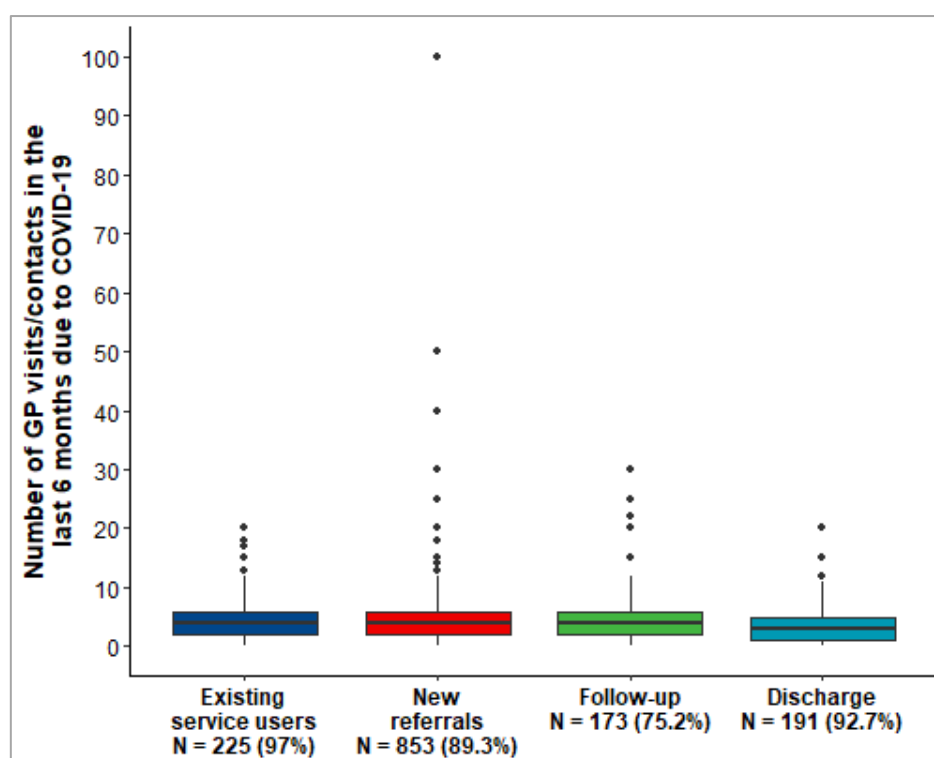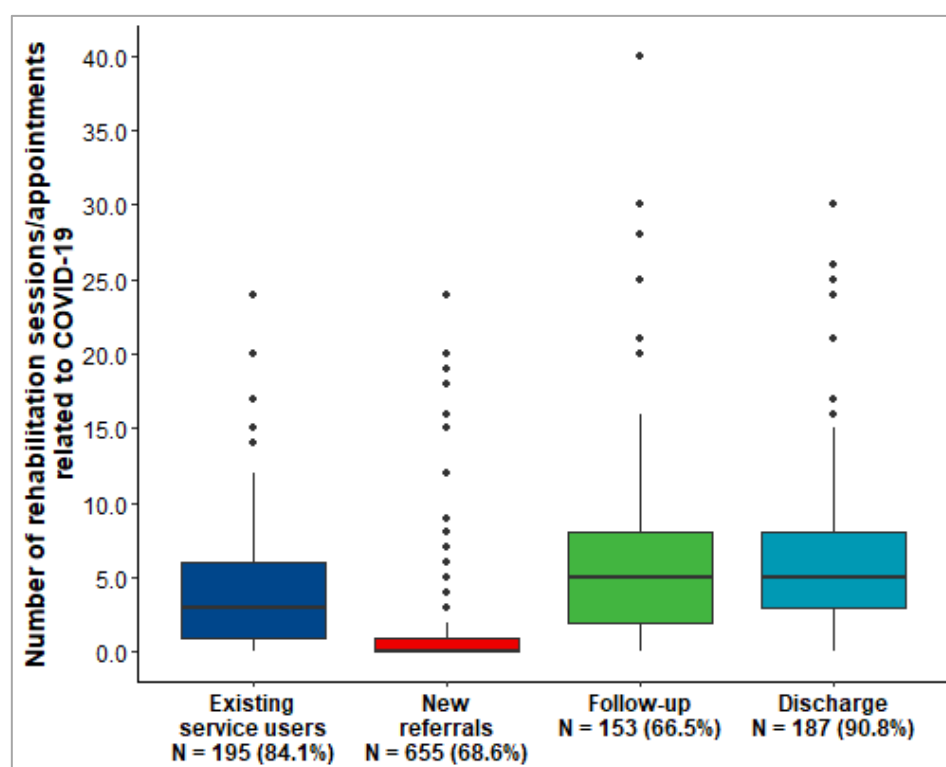

Figure 8. Box plots for: [Q7] *"Please tell us how many GP visits/contacts (face-to-face or remotely) you have had in the last 6 months related to COVID-19".* For each service user group, number of responders (N) and the % of total group responders are reported under the group label. (% of responses by LHB - AB UHB: 3.1%; BC UHB: 13.5%; CAV UHB: 18.9%; CTM UHB: 36.7%; HD UHB: 12.7%; PT HB: 2.4%; SB UHB: 12.9%).

4.5 Access to rehabilitation due to COVID-19 (Q8)

Responders were asked how many times they accessed rehabilitation due to COVID-19. Summary statistics and distribution plots are reported in Table 7 and Figure 9. The 'Follow-up' and 'Discharge' groups had a median of 5 rehabilitation sessions, the 'Existing service users' group had 3 and the 'New referrals' group had 1. It is important to note that different LHBs implemented different types of rehabilitation for their Long COVID service users.

	Existing service users	New referrals	Follow-up	Discharge
Number of responders	195	655	153	187
% who answered the question	84.1%	68.6%	66.5%	90.8%
Minimum value	0	0	0	0
Median (IQR)	3 (1,6)	1 (0,1)	5 (2,8)	5 (3,8)
Maximum value	24	24	40	30

Table 7. Summary statistics for [Q8]: "*If you have had rehabilitation related to your COVID-19, please tell us how many sessions/appointments you have had?*" IQR = Inter-Quartile Range. (% of responses by LHB - AB UHB: 2.7%; BC UHB: 12.7%; CAV UHB: 16.1%; CTM UHB: 43.5%; HD UHB: 11.6%; PT HB: 2.2%; SB UHB: 11.3%).

Figure 9. Box plots for: [Q8] "*If you have had rehabilitation related to your COVID-19, please tell us how many sessions/appointments you have had*". For each service user group, number of responders (N) and the % of total group responders are reported under the group label. (% of responses by LHB - AB UHB: 2.7%; BC UHB: 12.7%; CAV UHB: 16.1%; CTM UHB: 43.5%; HD UHB: 11.6%; PT HB: 2.2%; SB UHB: 11.3%).

4.6 General quality of life: EQ-5D-5L (Q9-Q14)

Responses to the five EQ-5D-5L dimensions are reported in Figures 10-14. The main results have been summarised for each dimension.

EQ-5D-5L dimension: 'Mobility' (Figure 10). The most selected answer options were:

- For the 'Existing service users' group (33.6%): '*I have moderate problems in walking about*' (score 3)
- For the 'New referrals' group (32.5%): '*I have moderate problems in walking about*' (score 3)
- For the 'Follow-up' group (30.4%): '*I have no problems in walking about*' (score 1)
- For the 'Discharge' group (38.3%): '*I have no problems in walking about*' (score 1)

In all groups, < 2% of responders chose the most severe option (score 5) '*I am unable to walk about*'.
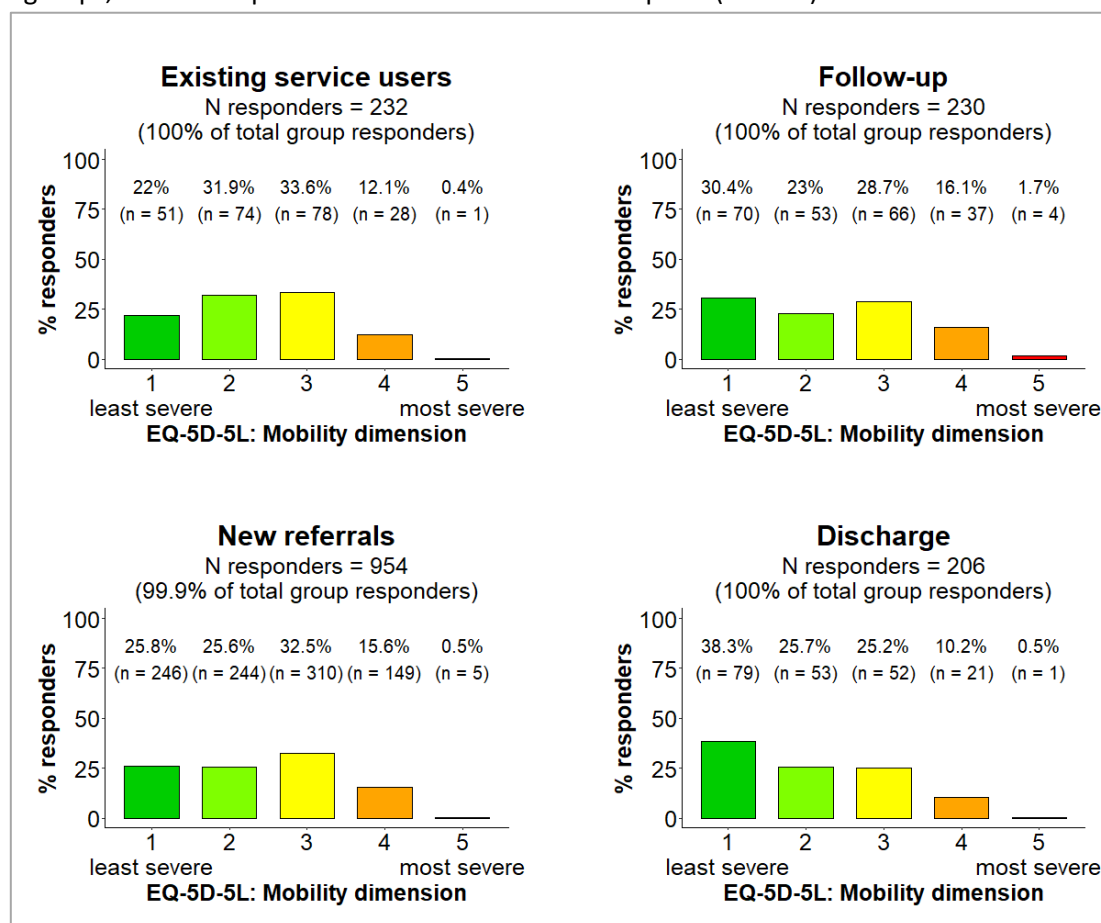
Figure 10. % Bar plots for: [Q9] "*Please select the option that best describes your health TODAY: MOBILITY*". N = number of responders for each service user group. n = number of group responders that chose the specific EQ-5D-5L dimension score. (% of responses by LHB - AB UHB: 9.9%; BC UHB: 12.8%; CAV UHB: 17.7%; CTM UHB: 33.4%; HD UHB: 12%; PT HB: 2.2%; SB UHB: 12%).

EQ-5D-5L dimension: 'Self-care' (Figure 11). The most selected answer options were:

- For the 'Existing service users' group (54.3%): '*I have no problems washing or dressing myself*' (score 1)
- For the 'New referrals' group (55.6%): '*I have no problems washing or dressing myself*' (score 1)
- For the 'Follow-up' group (50.4%): '*I have no problems washing or dressing myself*' (score 1)
- For the 'Discharge' group (65%): '*I have no problems washing or dressing myself*' (score 1)

In all groups, < 2% of responders chose the most severe option (score 5) '*I am unable to wash or dress myself*'.
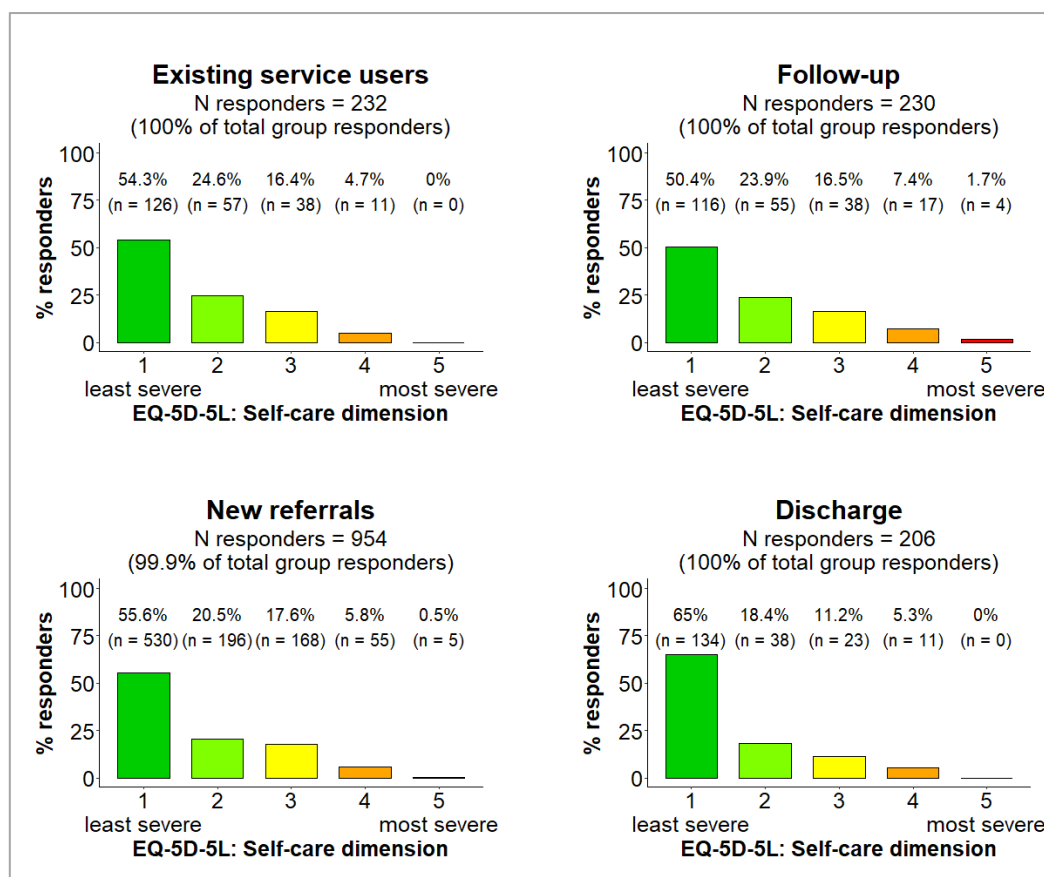
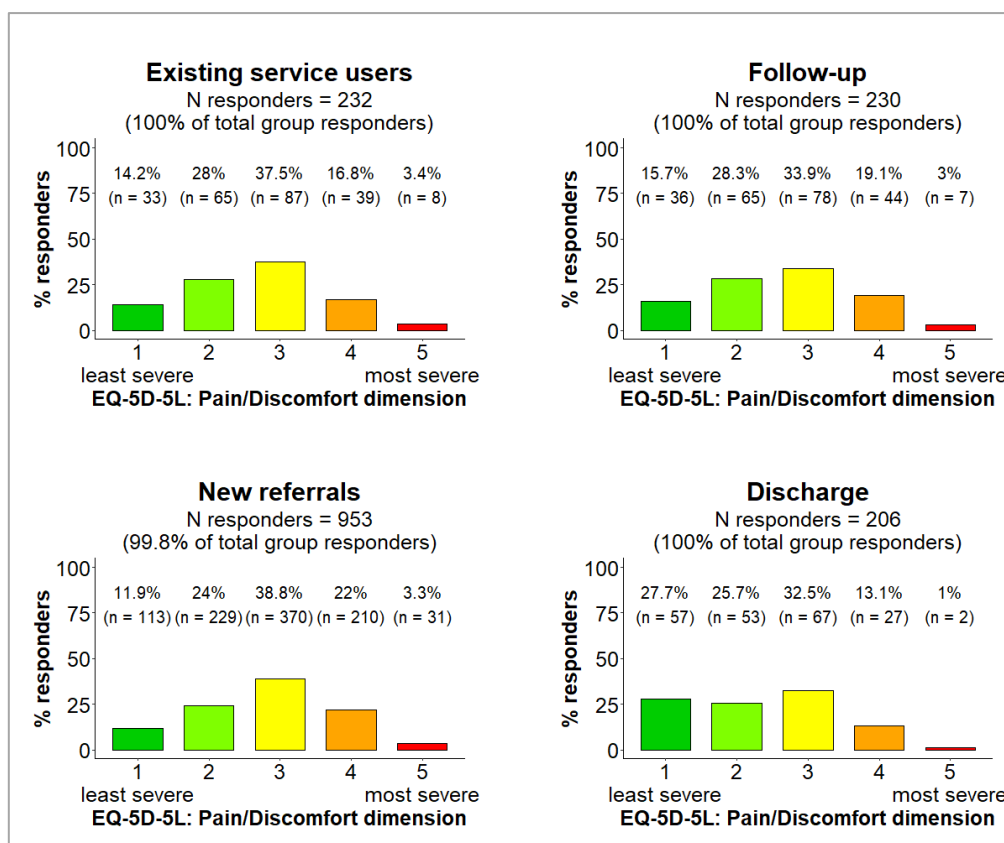**Figure 11. % Bar plots for: [Q10]** "*Please select the option that best describes your health TODAY: SELF-CARE*". N = number of responders for each service user group. n = number of group responders that chose the specific EQ-5D-5L dimension score. (% of responses by LHB - AB UHB: 9.9%; BC UHB: 12.8%; CAV UHB: 17.7%; CTM UHB: 33.4%; HD UHB: 12%; PT HB: 2.2%; SB UHB: 12%).

EQ-5D-5L dimension: 'Usual activities' (Figure 12). The most selected answer options were:

- For the 'Existing service users' group (37.5%): '*I have moderate problems doing my usual activities*' (score 3)
- For the 'New referrals' group (36.6%): '*I have moderate problems doing my usual activities*' (score 3)
- For the 'Follow-up' group (32.2%): '*I have moderate problems doing my usual activities*' (score 3)
- For the 'Discharge' group (34.5%): *I have moderate problems doing my usual activities*' (score 3)

In all groups, > 8% of responders chose the most severe option (score 5) '*I am unable to do my usual activities*' ('Follow-up': 13.5%; 'New referrals': 13.3%; 'Existing service users': 9.1%; 'Discharge': 8.7%).
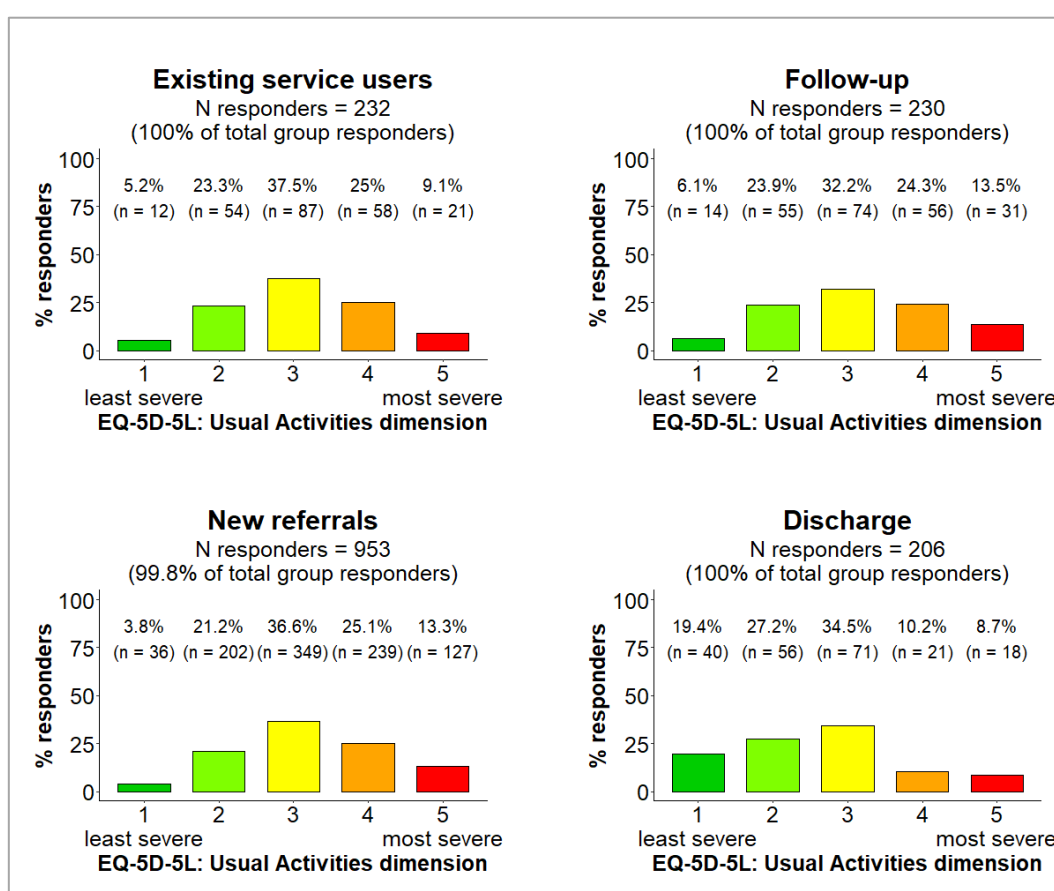
Figure 12. % Bar plots for: [Q11] "*Please select the option that best describes your health TODAY: USUAL ACTIVITIES*". N = number of responders for each service user group. n = number of group responders that chose the specific EQ-5D-5L dimension score. (% of responses by LHB - AB UHB: 9.9%; BC UHB: 12.8%; CAV UHB: 17.7%; CTM UHB: 33.4%; HD UHB: 12%; PT HB: 2.2%; SB UHB: 12%).

EQ-5D-5L dimension: 'Pain and discomfort' (Figure 13). The most selected answer options were:

- For the 'Existing service users' group (37.5%): '*I have moderate pain or discomfort*' (score 3)
- For the 'New referrals' group (38.8%): '*I have moderate pain or discomfort*' (score 3)
- For the 'Follow-up' group (33.9%): '*I have moderate pain or discomfort*' (score 3)
- For the 'Discharge' group (32.5%): '*I have moderate pain or discomfort*' (score 3)

In all groups, < 4% of responders chose the most severe option (score 5) '*I have extreme pain or discomfort*'.
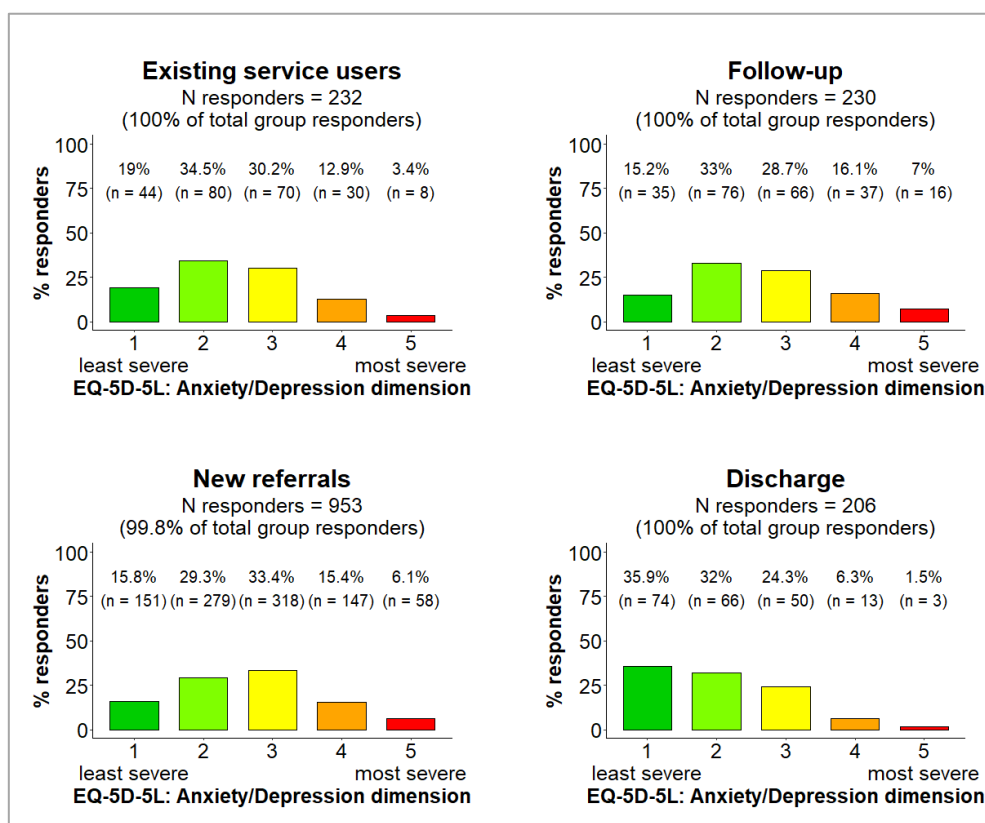

Figure 13. % Bar plots for: [Q12] "*Please select the option that best describes your health TODAY: PAIN & DISCOMFORT***".** N = number of responders for each service user group. n = number of group responders that chose the specific EQ-5D-5L dimension score. (% of responses by LHB - AB UHB: 9.9%; BC UHB: 12.8%; CAV UHB: 17.7%; CTM UHB: 33.4%; HD UHB: 12%; PT HB: 2.2%; SB UHB: 12%).

EQ-5D-5L dimension: 'Anxiety and depression' (Figure 14). The most selected answer options were:

- For the 'Existing service users' group (34.5%): '*I am slightly anxious or depressed*' (score 2)
- For the 'New referrals' group (33.4%): '*I am moderately anxious or depressed*' (score 3)
- For the 'Follow-up' group (33%): '*I am slightly anxious or depressed*' (score 2)
- For the 'Discharge' group (35.9%): '*I am not anxious or depressed*' (score 1)

In all groups, 7% or less of responders chose the most severe option (score 5) '*I am extremely anxious or depressed*'.

Figure 14. **% Bar plots for: [Q13] "*Please select the option that best describes your health TODAY: ANXIETY & DEPRESSION*".** N = number of responders for each service user group. n = number of group responders that chose the specific EQ-5D-5L dimension score. (% of responses by LHB - AB UHB: 9.9%; BC UHB: 12.8%; CAV UHB: 17.7%; CTM UHB: 33.4%; HD UHB: 12%; PT HB: 2.2%; SB UHB: 12%).

The EQ-5D-5L index was calculated for each responder by combining their EQ-5D-5L dimension scores (see Methods section 3.1.1). Results are reported in Table 8 and Figure 15. The 'Discharge' group had the highest median EQ-5D-5L index (0.68), while the 'New referrals' and 'Follow-up' groups had the lowest (0.53).

The statistical distributions of EQ-5D-5L index were significantly different across the four service user groups (Kruskal-Wallis test: H (3) = 56.0, p < 0.001). Those in the 'Discharge' group tended to have a significantly higher EQ-5D-5L index (indicating a higher quality of life) in comparison to all other groups (vs 'Existing service users': p < 0.001; vs 'New referrals': p < 0.001; vs 'Follow-up': p < 0.001).

It is important to remind that the responses across the four groups were not linked by responder (given all data were anonymous). Therefore, it is not possible to determine whether the higher values for the 'Discharge' group were due to individuals' improvement or to differences in some group's characteristics in comparison to the other three ones (e.g. individuals in the 'Discharge' group might have suffered of less severe Long COVID symptoms and not being represented in any of the other three groups).

	Existing service users	New referrals	Follow-up	Discharge
Number of responders	232	953	230	206
% for whom EQ-5D-5L Index was calculated	100%	99.8%	100%	100%
Minimum value	-0.283	-0.367	-0.594	-0.134
Median (IQR)	0.54 (0.3,0.7)	0.53 (0.3,0.7)	0.53 (0.2,0.7)	0.68 (0.5,0.8)
Maximum value	1	1	1	1

Table 8. Summary statistics for: EQ-5D-5L index. Calculated from scores [Q9]-[Q13]. IQR = Inter-Quartile Range. (% of responses by LHB - AB UHB: 9.9%; BC UHB: 12.8%; CAV UHB: 17.7%; CTM UHB: 33.4%; HD UHB: 12%; PT HB: 2.2%; SB UHB: 12%).
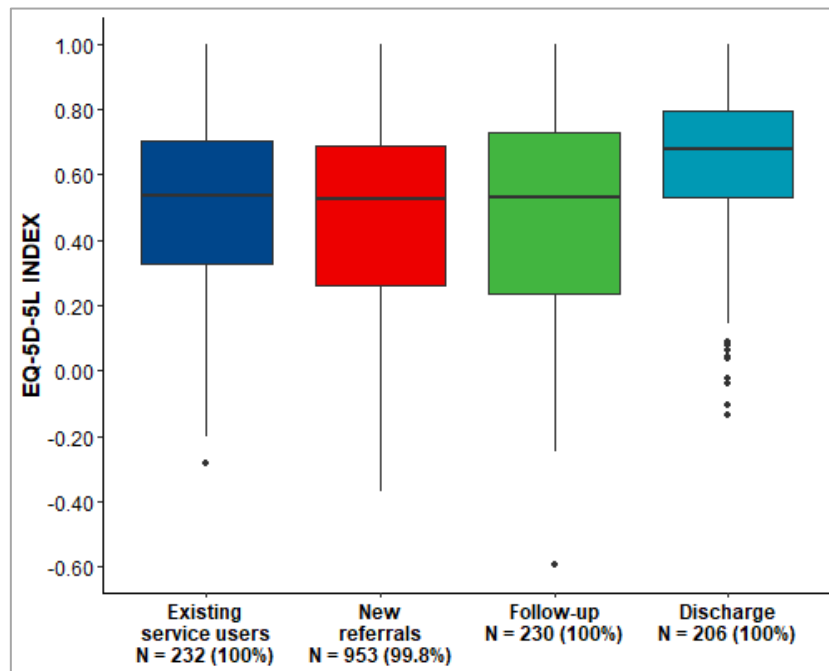
Figure 15. Box plots for: EQ-5D-5L index. Calculated from EQ-5D-5L scores [Q9]-[Q13]. For each service user group, number of responders (N) and the % of total group responders are reported under the group label. (% of responses by LHB - AB UHB: 9.9%; BC UHB: 12.8%; CAV UHB: 17.7%; CTM UHB: 33.4%; HD UHB: 12%; PT HB: 2.2%; SB UHB: 12%).

EQ-VAS results are reported for each group in Table 9 and Figure 16. The 'Discharge' group had the highest median EQ-VAS score (65), while all the other groups scored 50.

The statistical distributions of EQ-VAS were significantly different across the four service user cohorts (Kruskal-Wallis test: H (3) = 72.8, p < 0.001). Those in the 'Discharge' group tended to have a significantly higher EQ-VAS (indicating a higher quality of life) in comparison to all other groups (vs 'Existing service users': p < 0.001; vs 'New referrals': p < 0.001; vs 'Follow-up': p < 0.001). The same limitations explained above for the EQ-5D-5L index results (due to non-linkable anonymised data) must be considered for the EQ-VAS results as well.

	Existing service users	New referrals	Follow-up	Discharge
Number of responders	232	953	229	205
% who answered the question	100%	99.8%	99.6%	99.5%
Minimum value	0	0	0	5
Median (IQR)	50 (40,70)	50 (30,65)	50 (35,70)	65 (50,80)
Maximum value	95	100	100	100

Table 9. Summary statistics for: [Q14] *"We would like to know how good or bad your health is today (scale 0-100)"*. IQR = Inter-Quartile Range. (% of responses by LHB - AB UHB: 9.9%; BC UHB: 12.8%; CAV UHB: 17.7%; CTM UHB: 33.5%; HD UHB: 11.9%; PT HB: 2.2%; SB UHB: 12%).
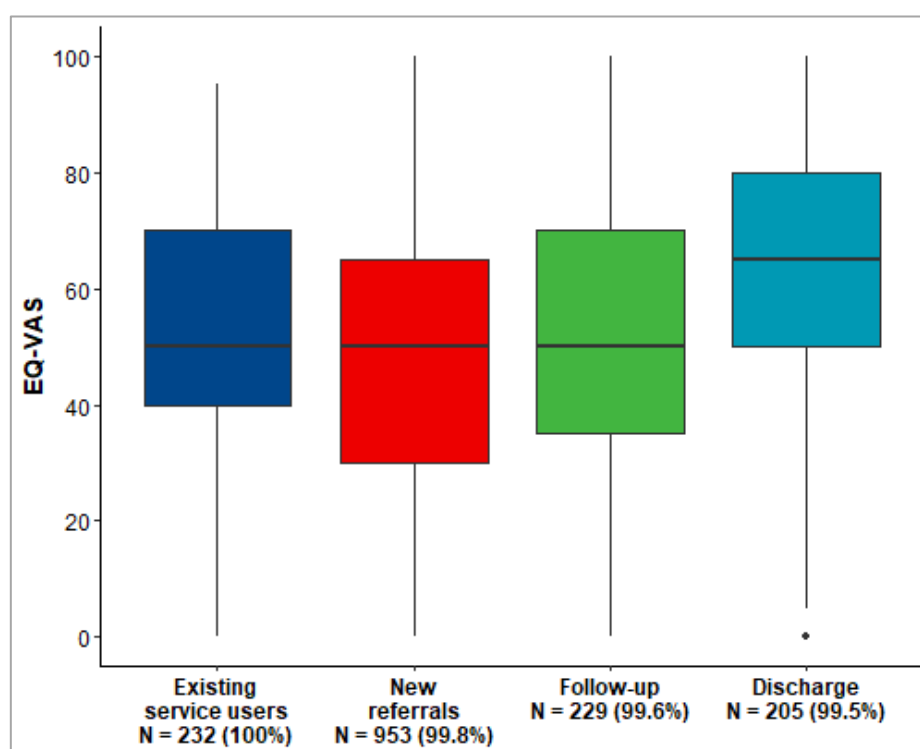

Figure 16. Box plots for: [Q14] *"We would like to know how good or bad your health is today (scale 0-100)"*. For each service user group, number of responders (N) and the % of total group responders are reported under the group label. (% of responses by LHB - AB UHB: 9.9%; BC UHB: 12.8%; CAV UHB: 17.7%; CTM UHB: 33.5%; HD UHB: 11.9%; PT HB: 2.2%; SB UHB: 12%).

4.7 Experience of the Long COVID service (Q15-Q21)

Responders were asked about their experiences with the Long COVID service. Responses were not collected from the 'New referrals' group, since their interaction with the service was assumed to be minimal.

Results for specific aspects of responders' experience are reported in Tables 10-12. In relation to the dimensions investigated (feeling listened to/understood, being supported to get the information needed and being involved in the support received), the highest proportion of responders from all groups ('Existing service users', 'Follow-up' and 'Discharge' groups) appeared satisfied with the Long COVID service.

PREM: 'Did you feel your concerns were listened to and understood?' (Table 10). Most of responders chose '*Always*' ('Discharge': 72.1%; 'Existing service users': 52%; 'Follow-up': 48.7%). The second most selected option was '*Sometimes*' ('Follow-up': 24.8%; 'Existing service users': 24%; 'Discharge': 11.3%).

Did you feel your concerns were listened to and understood?	Existing service users N = 225(97%)	Follow-up N = 230(100%)	Discharge N = 204(99%)
Always	117 (52%)	112 (48.7%)	147 (72.1%)
Usually	29 (12.9%)	50 (21.7%)	19 (9.3%)
Sometimes	54 (24%)	57 (24.8%)	23 (11.3%)
Never	25 (11.1%)	11 (4.8%)	15 (7.4%)

Table 10. Counts and percentages for [Q15]: "*Thinking about your overall first impressions of the Post COVID-19 Syndrome (Long COVID) service, did you feel your concerns were listened to and understood?*" In the table cells, percentages are calculated within each of the three service user cohorts. The intensity of the colour is proportional to the percentage (100% would get the maximum colour intensity). For each group, number of responders (N) and the % of total group responders are reported in the column header. (% of responses by LHB - AB UHB: 11%; BC UHB: 4.1%; CAV UHB: 20.1%; CTM UHB: 36.8%; HD UHB: 10.6%; PT HB: 3.8%; SB UHB: 13.7%).

PREM: 'Were you supported to get the information and help you needed?' (Table 11). Again, most of the responders in all groups chose '*Always*' ('Discharge': 66.2%; 'Existing service users': 51.3%; 'Follow-up': 43.5%). The second most selected option was either '*Usually*' ('Follow-up': 25.2) or '*Sometimes*' ('Existing service users': 22.1%; 'Discharge': 14.7%).

Were you supported to get the information and help you needed?	Existing service users N = 226(97.4%)	Follow-up N = 230(100%)	Discharge N = 204(99%)
Always	116 (51.3%)	100 (43.5%)	135 (66.2%)
Usually	34 (15%)	58 (25.2%)	20 (9.8%)
Sometimes	50 (22.1%)	55 (23.9%)	30 (14.7%)
Never	26 (11.5%)	17 (7.4%)	19 (9.3%)

Table 11. **Counts and percentages for [Q16]: "*Thinking about your overall first impressions of the Post COVID-19 Syndrome (Long COVID) service, were you supported to get the information and help you needed?"*** In the table cells, percentages are calculated within each of the three service user cohorts. The intensity of the colour is proportional to the percentage (100% would get the maximum colour intensity). For each group, number of responders (N) and the % of total group responders are reported in the column header. (% of responses by LHB - AB UHB: 11%; BC UHB: 4.1%; CAV UHB: 20%; CTM UHB: 36.7%; HD UHB: 10.5%; PT HB: 3.8%; SB UHB: 13.9%).

PREM: 'Were you involved enough in deciding what support you received?' (Table 12). The most selected answer in all groups was '*Always*' ('Discharge': 63.7%; 'Existing service users': 50.9%; 'Follow-up': 43.4%). The second most frequent answer was '*Usually*' for 'Discharge' (12.7%), '*Sometimes*' for 'Follow-up' (22.8%), and '*Never*' for the 'Existing service users' (17.9%).

Were you involved enough in deciding what support you received?	Existing service users N = 224(96.6%)	Follow-up N = 228(99.1%)	Discharge N = 204(99%)
Always	114 (50.9%)	99 (43.4%)	130 (63.7%)
Usually	31 (13.8%)	49 (21.5%)	26 (12.7%)
Sometimes	39 (17.4%)	52 (22.8%)	23 (11.3%)
Never	40 (17.9%)	28 (12.3%)	25 (12.3%)

Table 12. Counts and percentages for [Q17]: "*Thinking about your overall first impressions of the Post COVID-19 Syndrome (Long COVID) service, were you involved enough in deciding what support you received?*" In the table cells, percentages are calculated within each of the three service user cohorts. The intensity of the colour is proportional to the percentage (100% would get the maximum colour intensity). For each group, number of responders (N) and the % of total group responders are reported in the column header. (% of responses by LHB - AB UHB: 11.1%; BC UHB: 4.1%; CAV UHB: 19.7%; CTM UHB: 37%; HD UHB: 10.6%; PT HB: 3.8%; SB UHB: 13.8%).

Rating their overall 'Long COVID service experience' on a scale from 1 to 10 (Table 13), more than 65% of the responders selected an above average rate (>5): 78.6% of 'Discharge', 70.9% of 'Existing service users' and 65.5% of 'Follow-up'. In all groups, the highest proportion chose the maximum rate of 10 ('*Excellent*').

At the other end of the rating scale, 20.5% of 'Follow-up', 19.4% of 'Existing service users' and 13.4% of 'Discharge' rated their experience as below average (< 5).

Using a scale of 0-10 where 0 is very bad and 10 is excellent, how would you rate your overall experience?	Existing service users N = 227(97.8%)	Follow-up N = 229(99.6%)	Discharge N = 201(97.6%)
0 (Very bad)	9 (4%)	6 (2.6%)	7 (3.5%)
1	9 (4%)	6 (2.6%)	3 (1.5%)
2	8 (3.5%)	6 (2.6%)	7 (3.5%)
3	10 (4.4%)	16 (7%)	6 (3%)
4	8 (3.5%)	13 (5.7%)	4 (2%)
5 (Average)	22 (9.7%)	32 (14%)	16 (8%)
6	16 (7%)	12 (5.2%)	10 (5%)
7	23 (10.1%)	25 (10.9%)	12 (6%)
8	27 (11.9%)	22 (9.6%)	25 (12.4%)
9	21 (9.3%)	22 (9.6%)	27 (13.4%)
10 (Excellent)	74 (32.6%)	69 (30.1%)	84 (41.8%)

Table 13. Counts and percentages for [Q18]: "*Using a scale of 0-10 where 0 is very bad and 10 is excellent, how would you rate your overall experience?*" In the table cells, percentages are calculated within each of the three service user cohorts. The intensity of the colour is proportional to the percentage (100% would get the maximum colour intensity). For each group, number of responders (N) and the % of total group responders are reported in the column header. (% of responses by LHB - AB UHB: 11%; BC UHB: 4.1%; CAV UHB: 20.1%; CTM UHB: 36.6%; HD UHB: 10.3%; PT HB: 3.8%; SB UHB: 14.1%).

A total of 135 responders (85 from "Follow-up" and 50 from "Discharge" groups) provided further feedback in regards of their service experiences via free text (responses collected between the 1st of April 2022 to the 31st of May 2022; see previously published reports for thematic analysis of earlier responses: https://cedar.nhs.wales/our-work/evaluation/adferiad-recovery-long-covid-evaluation/). Results were summarised by identifying core themes and representative quotes: Table 14 contains positive feedback, Table 15 negative feedback and Table 16 suggestions for improvement.

Themes (Positive feedback)	Follow-up N = 85	Discharge N = 50
Excellent support from the Long COVID service • *"The COVID Clinic was excellent"* • *"The support was amazing."* • *"Excellent support service."*	5	1
Responders felt put at ease, listened to and acknowledged by the Long COVID team • *"Staff I have spoken to have always been very kind and sympathetic."* • *"I was listened to, they were very understanding very helpful and helped me to feel better in myself"* • *"Only had 2 sessions, but I feel empathy and a good understanding of my needs."* • *"After my first visit I was told I could phone anytime, I have and they always listen to me and I feel better after our chat"* • *"Staff are friendly and compassionate they wore masks in my appointment which made me feel safer"* • *"Feels was taken seriously"* • *"They listened to me, felt like they understood wat I going through & believed I had Long COVID & not just pretending I was ill"*	27	21
Responders found the Long COVID service staff knowledgeable and the advice/treatment provided helpful • *"I learnt about living with Long COVID, strategies & coping techniques."* • *"Very informative. Provided information to help recover."* • *"Good advice and information provided by professional."* • *"Staff were very good and had a good range of knowledge."*	16	22
Responders mentioned specific components of the Long COVID service that improved their recovery • *"The dietician was helpful"* • *"The fatigue management course that I was invited to attend was very informative and useful."* • *"The Occupational Therapist who I had appointments with was very helpful and I felt that I was listened to by her."* • *"I was fully supported by SALT [Speech & Language Therapists]"* • *"Informative about breathing."* • *"Good advice - exercises for breathing and coughing."* • *"Exercises in gym very useful. Improved all strength goals."* • *"I have had support from a respiratory physiotherapist which has been very useful and helpful"*	13	15

Responders valued the group sessions, which allowed them to get mutual support, sharing and recognition from the interaction with other patients • *"[…] I now have a support group of other people in the same situation"* • *"Being supported in a group with people who understood what I was going through."* • *"The peer support groups were […] an opportunity to hear from other people who are also experiencing long-COVID, which helped me to feel less alone with having and living with the condition."*	4	2
Responders felt the Long COVID service was personalised around their needs • *"Free discussion, able to lead this in a way to talk about what was useful to me."*	4	5

Table 14. Positive service user experience feedback extracted from responders' answers to [Q19] "*Please tell us if there was anything particularly good about your experiences that you would like to tell us about?***" and [Q20] "***Please tell us if there is anything that we could change to improve your experience?***"** For each service user group, number of responders (N) are reported. Each responder might have contributed to more than one theme.**

Themes (Negative feedback)	Follow-up N = 85	Discharge N = 50
More medical diagnosis and testing available to facilitate treatment, not just rehabilitation • *"Dedicated, consultant led clinics are badly needed."* • *"I would have liked more medical intervention"* • *"I feel there should be more medical input to investigate and treat the cause of lung and nervous system inflammation. Goal driven recovery worsened my symptoms and should be avoided"* • *"Haven't yet heard any treatment suggestions which we're all hoping for. Diagnostic testing would be welcomed."* • *"Need more diagnostic equipment for people like me who have had no heart, lung or brain scans. Currently no available further diagnosis means rehab would hurt my chest."* • *"I asked for further investigations and have been completely dismissed and referred to a psychologist which was insulting and a complete waste of time I had asked to have dysautonomia and neurological"* • *"Focus has been on rehabilitation/pacing without identifying biomedical causes first. Lack of access to neurology assessment"* • *"More thorough investigations to individuals' symptoms."* • *"Get more Long COVID clinics and get bloods and tests done instead of the rehab offered, which is just exercise"*	18	3
The advice/treatment offered is too generic and not enough tailored around individual user's needs • *"The service didn't help me at all. I'd would improve it by having some actual solutions to the problems I was facing. The content focused on managing symptoms which firstly made me feel worse because there were no solutions to the underlying problems or any way to get better, and secondly were all things I had already found through Google meant that I found it useless"* • *"Not personalised enough although I understand why. Too many sessions where symptoms were discussed but not the strategies to deal with them."* • *"I feel I still haven't received practical support in dealing with pacing to avoid post exertional symptoms."* • *"I don't feel unfortunately that each sufferer is being dealt with individually, filling in questionnaires may be useful for statistics but not for the sufferers. I do not feel I have received any benefit because of this approach."* • *"Feels other issues that could have been addressed and always felt went back to breathing."* • *"One of my answers was misinterpreted and felt then all the sessions were focused on the wrong thing. Too generic and not personal enough."* • *"I attended a Long COVID video support group - I found that everyone was at different stages in their recovery so I didn't find it beneficial"* • *"This questionnaire does not take into account variations in health in a given day from example morning to afternoon. It only says how are you today".* • *"I was offered online breathing courses. And physiotherapy. Neither of which I need."* • *"I am concerned that treatment is restricted to one thing and does not always cover multiple issues."*	12	5

Responders prefer face-to-face support • *"More face to face session availability to reduce waiting times for individuals if possible."* • *"Hard over the phone. Face to face would be useful."* • *"The instructors are very good but limited as to what can be done, they do the best with the lack of facilities they have with doing it on line"*	7	18
Referral/access to the Long COVID service is too slow • *"Had a letter back on the waiting list rang up a month later 'where am I on the List'. YES, 119 WEEKS THAT IS 2 YEARS and 4 MONTHS --Your having a laugh I'll be dead by then UNLESS YOU SEE TO THESE PEOPLE IMMEDIATELY THERE WILL BE NO QUALITY OF LIFE I'M 75yrs now?????"* • *"It took a long time to get to the Long COVID clinic, felt I could have done with the support earlier on. Was a year and a half till I was with the clinic."* • *"It took too long from referral to appointment"* • *"Long COVID clinics exist but I have been waiting almost 7 months for an appointment following referral. It took me a year to get referred!"* • *"I would like to have been helped earlier when I came home from hospital."* • *"I had COVID in March 2020 and developed Long COVID around May 2020. […] To date, I remain on the waiting list for the Long COVID rehabilitation service and have had to find my own way through treatment*	12	0
Various communication issues • *"My first assessment was completed by a member of staff I had previously worked with, so this made me feel uncomfortable."* • *"My GP told me I had Long COVID after 8 weeks or being poorly, Occupational health and the Long COVID clinic told me I had to be symptomatic for 12 weeks before I could be diagnosed. This was very confusing to me as I had 3 people telling me different things."* • *"Make notes that if read by others they fully understand any multiple issues the patient has rather than you having to either go through it all again"* • *"My wife says that the communication with my family could have been improved"* • *"The communication could be a bit better. I wasn't informed that the Occupational Therapist couldn't attend an appointment due to illness; I only found out when I phoned to enquire about the appointment being missed and to make another appointment."*	4	3
Uncertain support after Long COVID service discharge • *"Feels ongoing support would have been a benefit following initial intervention. Unclear where to go if experiencing further issues - signposting. Benefit from other interventions after Long COVID service".* • *"Feels discharged to early"* • *"More support long term, especially for mental health."* • *"Psychologist was initially helpful but insufficient follow up."*	4	3

• *"There has been no follow up support since my phone appointment with the Long COVID team"*		
Responders needed to find support independently • *"I had to find my own dietitian and I am having private physio to help relieve the tight muscles around my ribs."* • *"My GP tried to monitor my condition but were honest and open and said they didn't know how to help me. I paid private but couldn't continue because I was on the sick with zero pay."* • *"Most of my recovery I have done myself, I have created walking/yoga plans to slowly build up my stamina. Though the info I was sent was informing there was no plan to follow which I think would be beneficial. "*	3	0
Responders need more support with their job employers • *"Get our managers to understand what we are going through"* • *"Would like more post COVID help in work"*	3	1

Table 15. **Negative service user experience feedback (specific for Long COVID Service) extracted from responders' answers to [Q19] "***Please tell us if there was anything particularly good about your experiences that you would like to tell us about?***" and [Q20] "***Please tell us if there is anything that we could change to improve your experience?***"** For each service user group, number of responders (N) are reported. Each responder might have contributed to more than one theme.

Themes (Suggestions for improvement)	Follow-up N = 85	Discharge N = 50
More appointments should be made available at accessible times for people who work: • *"I would have liked to attend the rehab course for NHS staff but it was always at a lunchtime on a Tuesday, which isn't really a practical time if you work on Tuesdays. I appreciate it would be very difficult to accommodate everyone but it perhaps would have been helpful if possible to have a course held on another day as well, or for the course to have been either early or late in the day so that service users could request with work to start late / leave early for the course"* • *"Have an afternoon group"* • *"More evening (out of hours) appointments as in work."* • *"Discussions on online zoom times. All the times given I was in work"* • *"Physical group sessions within the initial 8 weeks were sometimes awkward to fit in amongst work commitments as they were set times/days."* Other suggestions: • *"When been referred to another department regarding your symptoms, you should not be referred back to your GP to do the referral. Rehabilitation team for COVID-19 should be able to do all referrals also to able to help with your symptoms and give support."* • *"More patient engagement. Split session into patient engagement and then lecture instead of just being lecture."* • *"The service needs to provide patients with aims and objectives before an appointment indicating what they can provide. What there is for Long COVID patients is limited you need to offer better support and services"* • *"A way for individuals to access up to date information (given ongoing research) e.g. brain fog."* • *"Drop in clinics - face to face."* • *"Would be useful if names of staff [were] listed on appointment letter when speaking to multiple team members."*	15	10

Table 16. **Suggestions for improvement of the Long COVID service extracted from responders' answers to [Q19] "***Please tell us if there was anything particularly good about your experiences that you would like to tell us about?***" and [Q20] "***Please tell us if there is anything that we could change to improve your experience?***"** For each service user group, number of responders (N) are reported. Each responder might have contributed to more than one theme.

Finally, as shown in Figure 17, the majority of responders would recommend the Long COVID service: 89.1% of the 'Discharge' group, 88.3% of the 'Existing service users' and 81.9% of the 'Follow-up' group.
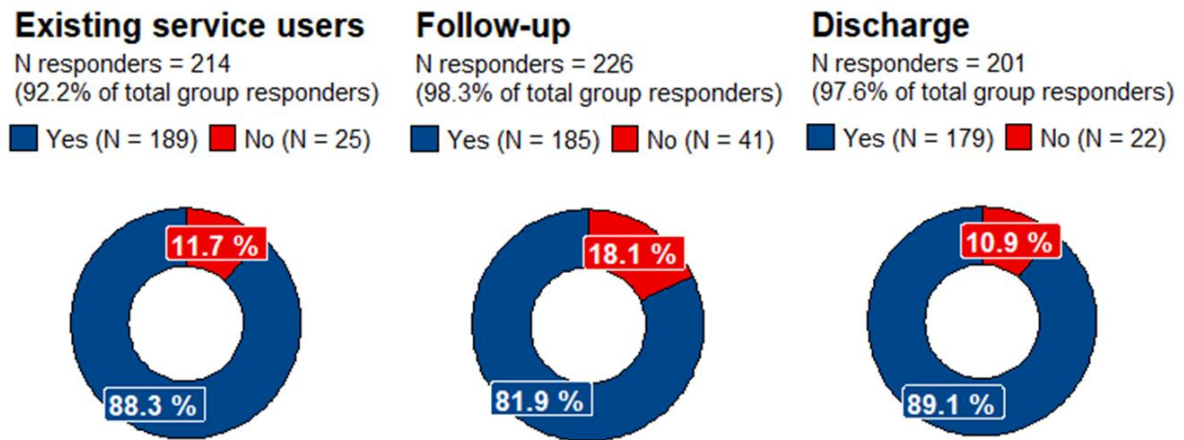

Figure 17. **Donut charts for [Q21]: "*Would you recommend this service?*"** (% of responses by LHB - AB UHB: 11%; BC UHB: 4.2%; CAV UHB: 19.4%; CTM UHB: 37.5%; HD UHB: 10.7%; PT HB: 3.7%; SB UHB: 13.5%).

4.8 Analysis of additional responses

A total of 203 responses were excluded from the main analysis following the criteria described in Section 3.1.5. These extra responses, from responders who did not access the Long COVID service, were analysed separately below.

Starting with their demographics (Table 17, Figure 18 and Figure 19), the majority of additional responders were females (75.9%,), the most frequent age range was 41-50 (36%), most responders were of '*Any White background*' ethnicity (96.1%) and the most frequent employment status was '*Full-time employed/self-employed*' (42.9%).

		Additional responders
	Total sample size	**203 (100%)**
Gender	**Female**	**154 (75.9%)**
	Male	48 (23.6%)
	Non-Binary	1 (0.5%)
	Prefer not to say	0 (0%)
Age range	**17 and under**	1 (0.5%)
	18 - 30	4 (2%)
	31 - 40	31 (15.3%)
	41 - 50	**73 (36%)**
	51 - 60	71 (35%)
	61 - 70	22 (10.8%)
	71 - 80	1 (0.5%)
	81 - 90	0 (0%)
	91 and over	0 (0%)
Language used to respond	**English**	**203 (100%)**
	Welsh	0 (0%)

Table 17. Demographics of additional responders.

'Additional' survey responders
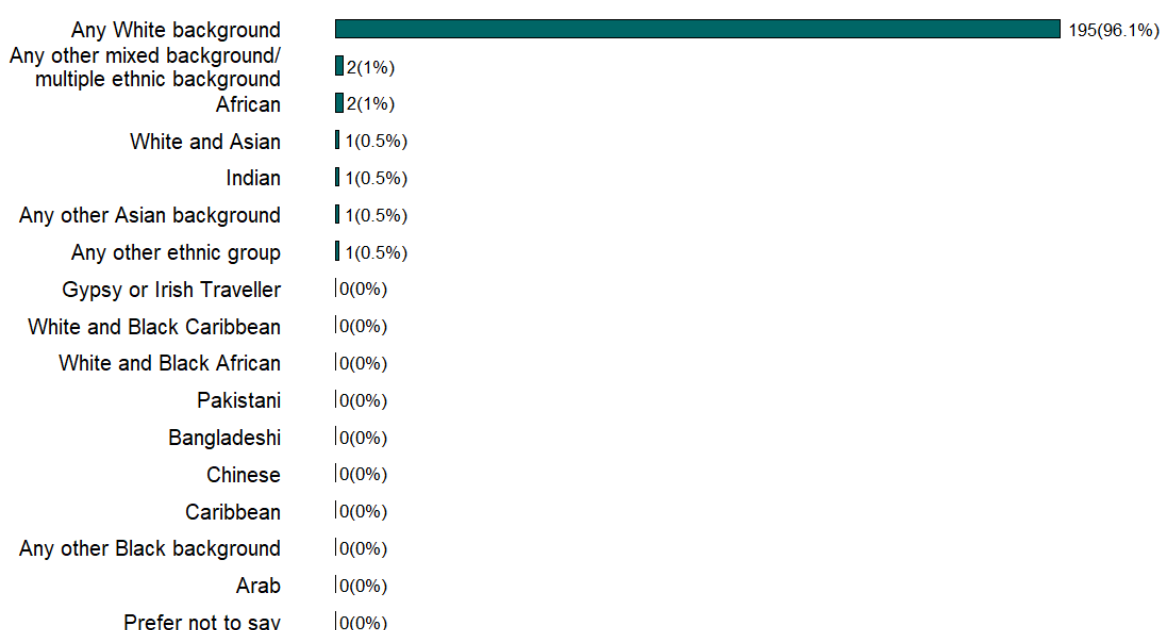N responders = 203 (100% of total group responders)

Any White background	195(96.1%)
Any other mixed background/ multiple ethnic background	2(1%)
African	2(1%)
White and Asian	1(0.5%)
Indian	1(0.5%)
Any other Asian background	1(0.5%)
Any other ethnic group	1(0.5%)
Gypsy or Irish Traveller	0(0%)
White and Black Caribbean	0(0%)
White and Black African	0(0%)
Pakistani	0(0%)
Bangladeshi	0(0%)
Chinese	0(0%)
Caribbean	0(0%)
Any other Black background	0(0%)
Arab	0(0%)
Prefer not to say	0(0%)

Figure 18. Bar plots for: [Q3] "*Please tell us your ethnicity*".

'Additional' survey responders
N responders = 203 (100% of total group responders)

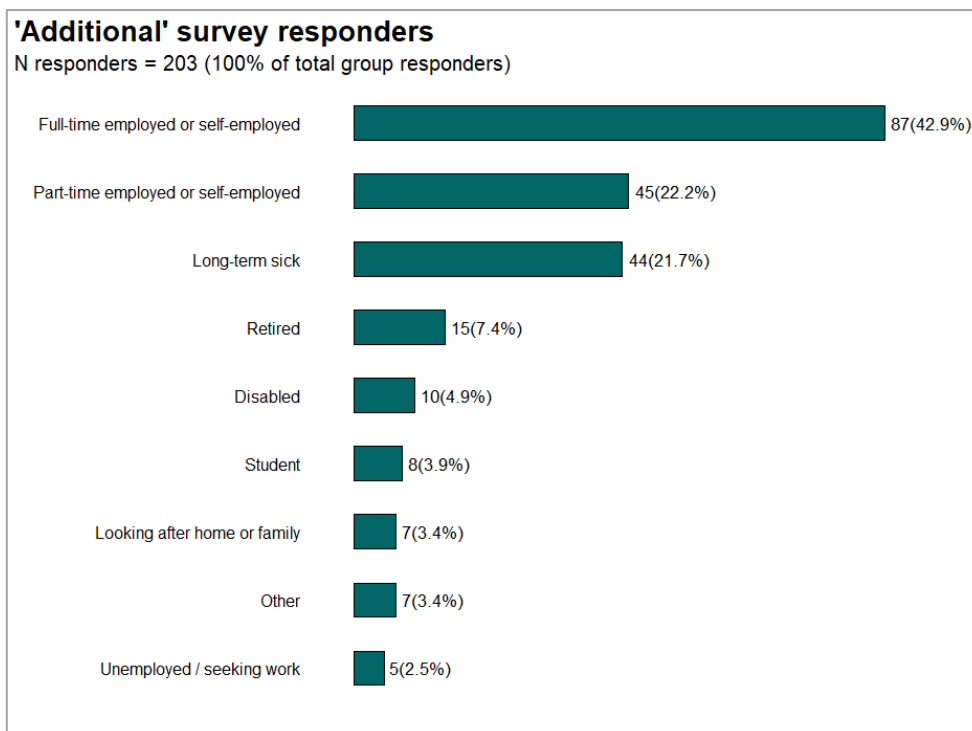|	
Full-time employed or self-employed	87(42.9%)
Part-time employed or self-employed	45(22.2%)
Long-term sick	44(21.7%)
Retired	15(7.4%)
Disabled	10(4.9%)
Student	8(3.9%)
Looking after home or family	7(3.4%)
Other	7(3.4%)
Unemployed / seeking work	5(2.5%)

Figure 19. Bar plots for: [Q4] "*Which of these definitions describe your employment status?*" Multiple responses per responder were allowed for this question (i.e., for each bar, 100% would represent that all responders chose that option).

The COVID-19 related symptoms experienced by the majority of additional responders were: '*Fatigue*' (89.7%), '*Brain fog*' (85.7%), '*Shortness of breath*' (76.8%), '*Joint pain*' (68%), '*Insomnia*' (60.1%), '*Headache*' (60.1%), '*Dizziness*' (57.1%), '*Chest pain/tightness*' (56.2%), '*Heart palpitations*' (54.7%) and '*Depression and anxiety*' (51.7%).
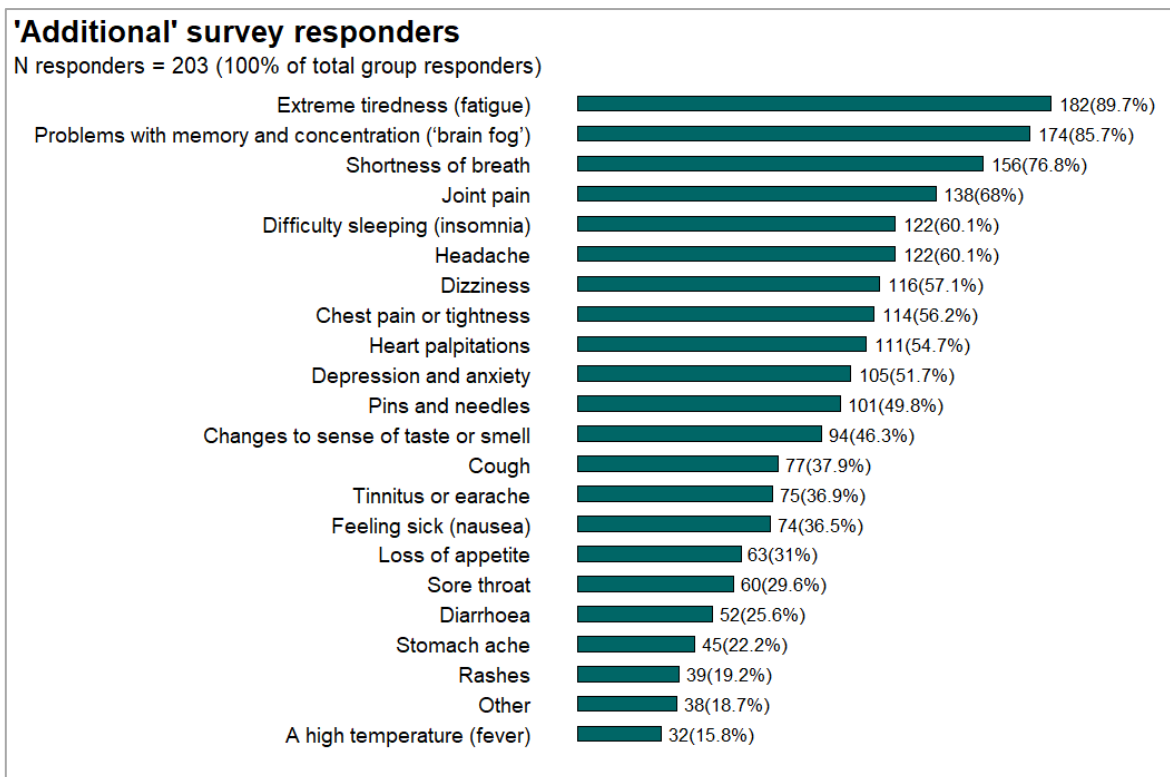
'Additional' survey responders
N responders = 203 (100% of total group responders)

Symptom	Value
Extreme tiredness (fatigue)	182(89.7%)
Problems with memory and concentration ('brain fog')	174(85.7%)
Shortness of breath	156(76.8%)
Joint pain	138(68%)
Difficulty sleeping (insomnia)	122(60.1%)
Headache	122(60.1%)
Dizziness	116(57.1%)
Chest pain or tightness	114(56.2%)
Heart palpitations	111(54.7%)
Depression and anxiety	105(51.7%)
Pins and needles	101(49.8%)
Changes to sense of taste or smell	94(46.3%)
Cough	77(37.9%)
Tinnitus or earache	75(36.9%)
Feeling sick (nausea)	74(36.5%)
Loss of appetite	63(31%)
Sore throat	60(29.6%)
Diarrhoea	52(25.6%)
Stomach ache	45(22.2%)
Rashes	39(19.2%)
Other	38(18.7%)
A high temperature (fever)	32(15.8%)

Figure 20. Bar plots for [Q6]: "*Please tell us about any symptoms you have experienced today due to COVID-19*". Multiple responses per participant were allowed for this question (i.e., for each bar, 100% would represent that all responders within the group chose that option).

Similar to what was reported by Long COVID service users, the 'additional' responders most frequently mentioned the following 'other' symptoms: '*Pain*', '*Mobility issues*', "*Post-exertional malaise*' (PEM), '*Vision and eye issues*' and problems with '*Voice, mouth, throat and/or swallowing*' (Table 18).

OTHER SYMPTOMS	'Additional' responders N = 37 (18.2%)
Pain (e.g. muscle pain/stiffness, general or localised pain in the body)	10
Mobility issues (including leg issues, balance issues, muscle weakness)	7
Post-exertional malaise	5
Vision and eye issues	5
Voice, mouth, throat and swallow issues	4
Hair loss	3
Cardiovascular issues (e.g. tachycardia)	2
Dysautonomia issues/Postural Orthostatic Tachycardia Syndrome (POTS)/ Orthostatic Intolerance	2
Gastrointestinal issues	2
Nose and/or sinus issues (e.g. nose bleed, nasal inflammation, sinus congestion)	2
Numbness of body (e.g. feet, face)	2
Vivid dreams, nightmares, waking up sharp with anxiety	2
Excessive sweating/feeling hot and/or inability to regulate body temperature	2
Allergy, MCAS (Mast Cell Activation Syndrome)	1
Constant muscle fasciculations	1
Issues with limb extremities (cold, sore, itching, swelling)	1
Flatulence	1
Swollen glands	1
Hearing loss	1
Hypersensitivity (e.g. to light, sound, pain or skin hypersensitivity)	1
Hypertension	1
Involuntary tremor	1
Mood issues (e.g. extreme mood swings, low mood)	1
Under-active thyroid	1
Transient ischemic attack	1

Table 18. 'Other symptoms' due to Long COVID not listed in the questionnaire. Number of responders (N) and the % of total responders are reported in the column head

No 'additional' responder provided feedback via free text (responses collected between the 1st of April 2022 to the 31st of May 2022; see previous published reports for thematic analysis of previous responses: https://cedar.nhs.wales/our-work/evaluation/adferiad-recovery-long-covid-evaluation/).

5. Local Health Boards demand data

Table 19 shows some demand data about access to the Long COVID service in the various LHBs. Given that different LHBs have implemented their Long COVID service in different ways, these numbers are only indicative and comparisons are not recommended.

Question	AB UHB	BC UHB	C&V UHB	CTM UHB	HD UHB	PT HB	SB UHB
Number of individuals who have been referred to the Long COVID service	289	969	521 (Total referred = 694, duplicate referrals = 62, inappropriate referrals = 111)	823	368	101	361
Number of individuals who have got access to and used the Long COVID service	153	291	469 (52 on waiting list, 260 failed to opt-in/refused appointment)	667	181	88	292
Number of Long COVID service users who have been referred to secondary care as outpatients	18	8	40	59	0	3	No direct secondary care referrals from Long COVID services. Patients are referred back to GP for any further investigations, this is mainly cardiology.

Table 19.Demand for accessing the Long COVID service.

Table 20 shows when the information was collected for Table 19.

Local Health Board	From	To
AB UHB	01/09/2021	30/06/2022
BC UHB	02/12/2021*	30/06/2022
C&V UHB	01/09/2021	30/06/2022
CTM UHB	01/07/2021	30/06/2022
HD UHB	01/10/2021	30/06/2022
PT HB	01/09/2021	30/06/2022
SB UHB	01/09/2021	15/06/2022

Table 20. Collection period of service demand data from LHBs. * Date when the Long COVID service went live for BC UHB.

6. References

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7. Supplementary Material

Appendix 1: National 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^{TM} 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

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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

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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

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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.

The best health
you can imagine

100
90
80
70
60
50
40
30
20
10
0

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

Appendix 2: Extra questions administered via social media survey questionnaire and classification of responders into service user groups

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' <u>or</u> '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' <u>Or</u> 'I am waiting to receive my first appointment/support from the Long COVID Service'