‘Adferiad’ (Recovery) Long COVID Service National Evaluation

(April 2022 update)

Canolfan Gwerth mewn Iechyd Cymru
Welsh Value in Health Centre

Cedar
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Contents

Summary

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

- The data collected includes: 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 (612 responders), 'Follow-up' (121 responders) and 'Discharge' (148 responders). In all four groups: the majority were female, the most frequent age range was 41-60, 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*', '*Insomnia*' and '*Depression and anxiety*'. Some users reported as additional symptoms '*General pain*', '*Voice, mouth, throat and/or swallowing problems*', various '*Mobility issues*' and '*Vision and eyes' issues*'.

- In all four service user groups, 21.6%-24% had to be admitted to hospital due to COVID-19. The 'Discharge' group spent a median of 20 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'= 0.69; for the other groups the index ranged 0.53-0.56). A similar result was obtained using the EQ-VAS ('Discharge group'= 65; for all other groups= 50).

- 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*' ('New referrals': 14.8%; 'Follow-up': 13.2%; 'Existing service users': 9.1%; 'Discharge': 8.8%). For all the remaining EQ-5D-5L dimensions ('Mobility', 'Self-care', 'Pain/discomfort' and 'Anxiety/depression'), < 6% of responders in all groups chose the most severe option.

- When asked about their experiences with the Long COVID service, the majority of responders in all groups reported that they '*always*' felt '*their concerns were listened to/understood*', and that they were '*supported to get the help and information they needed*'. More responders said that they were '*always involved enough in deciding what support they received*' than any other answer option. More than 70% of responders rated their overall experience with the Long COVID service above average (i.e. >5), and more than 88% would recommend the service.

- In the free text feedback about service user experience, many responders expressed their gratitude to the Long COVID service for feeling listened to and acknowledged, having received helpful treatment and advice and been put in touch with other fellow sufferers who can understand what they are going through. However, other responders urged the service to become more tailored around different users' needs. They suggested support should expand beyond rehabilitation/symptoms' management and develop tighter links with medical consultants, since this would allow prompt medical testing and diagnosis to inform treatment. Some responders would prefer more face-to-face appointments, now that rules allow, and longer/more frequent sessions. Keeping service users up-to-date with research developments in Long COVID treatment was mentioned as beneficial.

- A Social Return on Investment (SROI) analysis, for two Local Health Boards, identified that key outcomes for service users were feeling listened to and believed; being part of a group leading to a sense of community; better health; feeling cared about; and feeling able to cope. The SROIs were calculated as a ratio greater than 5, meaning that for every £1 invested there was a social return greater than £5, with almost all sensitivity analysis scenarios remaining with a ratio greater than 1.

1 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.

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, 2021b; Sudre et al., 2021; Whitaker et al., 2021).

The Office for National Statistics (ONS, 2021a) reported that in a random sample of 20,000 people surveyed from the UK community who tested positive for COVID-19, 13.7% continued to experience symptoms for at least 12 weeks. The estimated prevalence of long-term sequelae in hospitalised COVID-19 cases was reported to be higher, with 50%-89% of hospitalised individuals experiencing one or more chronic symptoms 2 months after infection (Lopez-Leon et al., 2021; NIHR, 2021).

In a recent update from the ONS (four-week period up to the 31st of October 2021), 55,000 people in Wales self-reported Long COVID symptoms (ONS, 2021b). It was estimated that for 11,000 of them (20%) the symptoms were substantially limiting their ability to carry out daily activities.

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. A first interim national evaluation report was developed and shared with WG on the 14th of January 2022 (https://cedar.nhs.wales/our-work/evaluation/adferiad-recovery-long-covid-evaluation/).

Since the Adferiad funding was allocated in September 2021, a significant effort and pace was required by the LHBs to recruit staff and establish services in the following months. Therefore, the first national evaluation report released in January offered a limited overview on the efficacy of the Adferiad programme, since some of the LHBs had just started to provide a Long COVID service and the data available was modest. 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 additional data to the analysis (up to the 31st of March 2022).

This report contains the analysis and summary of patient-reported outcome and experience measures (PROM and PREM) data collected at a national level via a cross-sectional survey (Sections 2.1 and 3). Data was collected from four groups of Long COVID service users in Wales, with the final aim to describe and compare their health status and opinions 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
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 March 2022

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

In addition to the survey questionnaire, two of the LHBs (C&V UHB and CTM UHB) asked Cedar to carry out a Social Return on Investment (SROI) analysis of their Long COVID Rehabilitation service. The main results are summarised in this report (Sections 2.2 and 4).

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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)

Finally, in order to provide further context, information collected from each LHB about their service demand is presented at the end of this report. This includes definitions of those allowed access to the (Sections 2.3 and 5).

2 Methods

2.1 National service user questionnaire data collection

The data was collected from the 1st of September 2021 to the 31st of March 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. Hywel Dda 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 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 (Q)	Description	Administered to
Your Long COVID support	Question 0 (Q0)	Service users were explicitly asked to indicate which LHB they were referred to for access to 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, plus optional Q4a)	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 measure	All groups
About your experience	Questions 15-21 (Q15-Q21)	Service users' thoughts and opinions 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), plus two additional questions (Q22 and Q23, see Appendix 2) to identify the service user group of the responder.

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

2.1.1 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).

2.1.2 Analysis of quantitative data

The responses from close-ended questions (i.e. excluding Q4a, Q6a, Q19 and Q20) were summarised as counts, percentages, medians and interquartile ranges. All percentages and statistics have been calculated separately within each service user group reported in Table 1.

Differences in the distributions of EQ-5D index and EQ-VAS across groups were tested using the Kruskal-Wallis H test, and 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, and Bonferroni correction was used to adjust the p-values. The statistical significance level was set at $p < 0.05$.

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

2.1.3 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 one of the authors and counts of themes per service user group were calculated using Excel and R.

For the two 'Long COVID service experience' 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 update report, only new free text responses to Q19 and Q20 were analysed (i.e. those collected from the 1st of January 2022 up to the 31st of March 2022). The aim was to identify any new emerging theme and confirm recurrent ones. Themes identified in the previous January report are available for reference in Appendices 3-7.

2.1.4 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 users). One problem with this methodology was that in the free text answers some responders declared to have had access to the service in one LHB although they were responding via a link corresponding to another one. To try to control this mismatch, we added an extra question (Q0) in the survey questionnaire from the 26th of January 2022 onwards, asking directly to responders from which LHB they were referred to for accessing the service. The answer provided by the responder (rather than the survey link) was used as reference to match them to a specific LHB.

2.1.5 Data filtering

Some responses were excluded from the main analysis (Sections 3.1-3.7) 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. This gave questionnaire access to those who may not have been representative of any of the service user groups. This led to a peak in responses, many of which were identifiable through 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 already been provided with a questionnaire link before they got any access.
- Responses collected via the 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 3.8) for demographics (Q1-Q4), COVID 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, and therefore it was decided to report their feedback as well.

2.2 Social Return of Investment

The approach used by Cedar is Social Return on Investment (SROI) rather than a cost-effectiveness analysis. SROI is a method of evaluating the impact of a service, by measuring changes that are relevant to the people or organisations that experience or contribute to the service. It seeks to explain and report how these changes are created, and measures them using monetary values that enable a ratio of benefits to costs to be calculated. However, it is primarily about the value that is created, and a tool to understand where this lies, who experiences that value, and how it comes about.

There were two reasons for this approach. Firstly, it became apparent that many of the important impacts on service users would not be well captured by the usual measures in an economic evaluation, and a narrow health care perspective may not be appropriate. Secondly, there were difficulties robustly collecting the data that would have been needed, due to changes in service provided, lack of Long COVID-specific clinical coding, and the importance of community services that would not be captured in databases such as the SAIL Databank.

SROI is a framework that follows a set of well-defined principles as described by Social Value UK (2012). Additional detail is available from Social Value UK, and from the interim reports submitted to the LHBs. The involvement of stakeholders throughout the process, and ensuring that outcomes that matter are identified and valued are core components, and this is paired with principles of transparency and avoidance of over-claiming. These principles have been used throughout the report, and additional information from stakeholders will be sought for the final report to improve valuation methods, and seek input from additional points of view.

Stakeholder views have been sought through the use of the National PROM and PREM data collection as well as interviews and an SROI-specific questionnaire. Details are in each LHB's full SROI report for April 2022.

2.3 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 used slightly different Long COVID definitions and started their Long COVID service 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).

3 Results of Long COVID Service National Survey

The survey collected 1311 service user responses, from the 1st September 2021 to the 31st of March 2022. 1271 (96.9%) of them were responses from users who accessed the survey using the email link provided by their LHB. The remaining 40 (3.1%) were collected from users who accessed the survey via a link shared on Cedar's social media account.

From the total, 1113 responses (84.9%) were included in the main analysis (Sections 3.1-3.7). The remaining 198 responses (15.1%) were analysed separately as 'additional responses' from individuals who did not access the service (Section 3.8).

Only 4 responders declared to have been referred to the Long COVID service of an LHB not matching the survey questionnaire link (3 responses for the AB UHB service, provided via C&V UHB link; and one response for C&V UHB service provided via AB UHB link).

3.1 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=612), while the 'Follow-up' group was the smallest (n=121). 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 (41.2% and 68.9%, respectively), while for 'Follow-up' they were from HD UHB (41.3%). In all four service user groups: the majority were female, the most frequent age range was 51-60 (except for group 'Follow-up', for which it was 41-50), 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%)**	**612 (100%)**	**121 (100%)**	**148 (100%)**	**1113 (100%)**
Health Board	**AB UHB**	22 (9.5%)	20 (3.3%)	3 (2.5%)	0 (0%)	**45 (4%)**
	BC UHB	0 (0%)	70 (11.4%)	4 (3.3%)	0 (0%)	**74 (6.6%)**
	C&V UHB	78 (33.6%)	89 (14.5%)	14 (11.6%)	17 (11.5%)	**198 (17.8%)**
	CTM UHB	77 (33.2%)	252 (41.2%)	33 (27.3%)	102 (68.9%)	**464 (41.7%)**
	HD UHB	0 (0%)	109 (17.8%)	50 (41.3%)	11 (7.4%)	**170 (15.3%)**
	PT HB	16 (6.9%)	9 (1.5%)	5 (4.1%)	1 (0.7%)	**31 (2.8%)**
	SB UHB	39 (16.8%)	63 (10.3%)	12 (9.9%)	17 (11.5%)	**131 (11.8%)**
Gender	**Female**	169 (72.8%)	400 (67%)	87 (71.9%)	85 (57.4%)	**741 (66.6%)**
	Male	63 (27.2%)	195 (32.7%)	34 (28.1%)	63 (42.6%)	**355 (31.9%)**
	Non-Binary	0 (0%)	1 (0.2%)	0 (0%)	0 (0%)	**1 (0.1%)**
	Prefer not to say	0 (0%)	1 (0.2%)	0 (0%)	0 (0%)	**1 (0.1%)**
Age range	**17 and under**	0 (0%)	0 (0%)	0 (0%)	0 (0%)	**0 (0%)**
	18 - 30	17 (7.3%)	40 (6.5%)	5 (4.1%)	5 (3.4%)	**67 (6%)**
	31 - 40	26 (11.2%)	102 (16.7%)	13 (10.7%)	15 (10.1%)	**156 (14%)**
	41 - 50	64 (27.6%)	153 (25%)	41 (33.9%)	37 (25%)	**295 (26.5%)**
	51 - 60	77 (33.2%)	192 (31.4%)	39 (32.2%)	50 (33.8%)	**358 (32.2%)**
	61 - 70	40 (17.2%)	88 (14.4%)	20 (16.5%)	33 (22.3%)	**181 (16.3%)**
	71 - 80	7 (3%)	34 (5.6%)	3 (2.5%)	8 (5.4%)	**52 (4.7%)**
	81 - 90	1 (0.4%)	3 (0.5%)	0 (0%)	0 (0%)	**4 (0.4%)**
	91 and over	0 (0%)	0 (0%)	0 (0%)	0 (0%)	**0 (0%)**
Language used to respond	**English**	231 (99.6%)	611 (99.8%)	119 (98.3%)	147 (99.3%)	**1108 (99.6%)**
	Welsh	1 (0.4%)	1 (0.2%)	2 (1.7%)	1 (0.7%)	**5 (0.4%)**

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

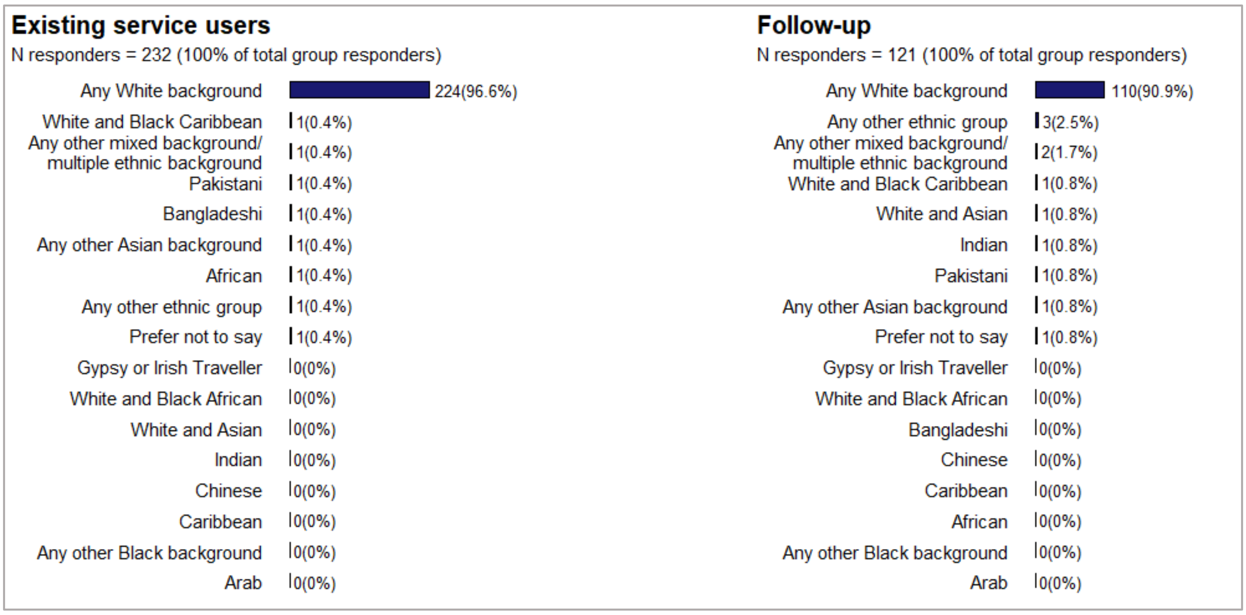


Figure 1. **Bar plots for:** [**Q3**] **"*Please tell us your ethnicity*".** Data for 'Existing service users' and 'Follow-up' service user groups. The numbers at the end of each bar indicate number of responders and percentage for each answer option within each group. (% of responses by LHB - AB UHB: 4%; BC UHB: 6.6%; CAV UHB: 17.8%; CTM UHB: 41.7%; HD UHB: 15.3%; PT HB: 2.8%; SB UHB: 11.8%)

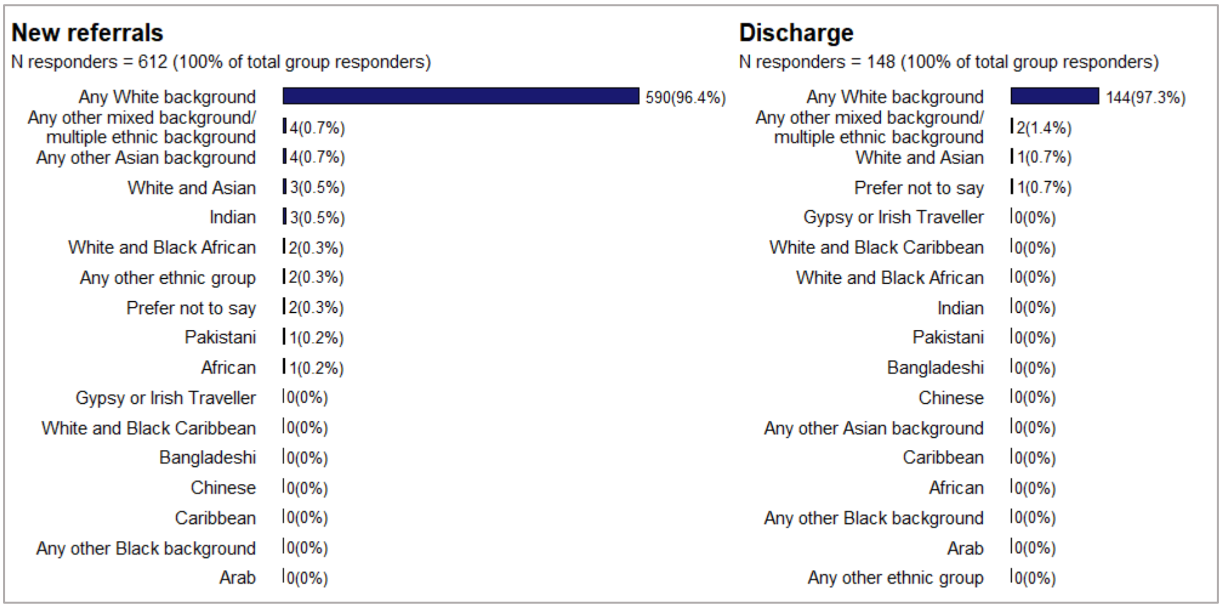


Figure 2. Bar plots for: [**Q3**] **"*Please tell us your ethnicity*".** Data for 'New referrals' and 'Discharge' service user groups. The numbers at the end of each bar indicate number of responders and percentage for each answer option within each group. (% of responses by LHB - AB UHB: 4%; BC UHB: 6.6%; CAV UHB: 17.8%; CTM UHB: 41.7%; HD UHB: 15.3%; PT HB: 2.8%; SB UHB: 11.8%)

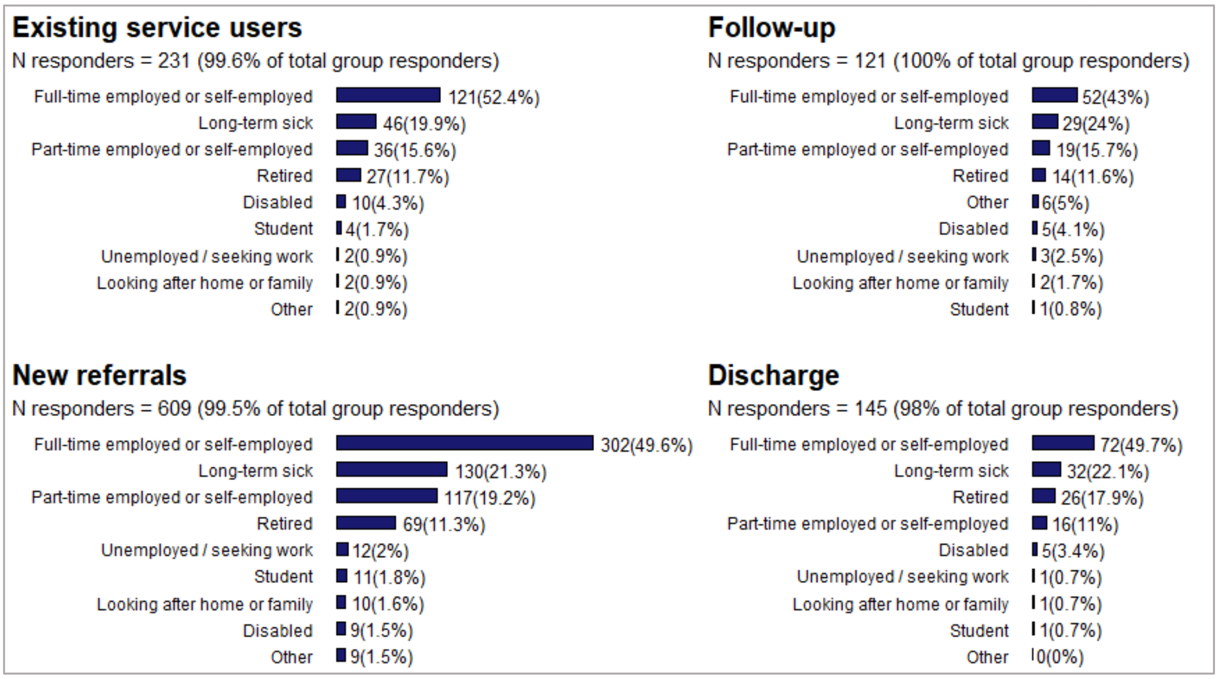


Figure 3. Bar plots for: [**Q4**] **"*Which of these definitions describe your employment status?*"** Multiple responses per participant were allowed for this question (i.e., for each bar, 100% would represent all responders within the group chose that option). (% of responses by LHB - AB UHB: 4.1%; BC UHB: 6. 7%; CAV UHB: 17.9%; CTM UHB: 41.5%; HD UHB: 15.2%; PT HB: 2.8%; SB UHB: 11.8%)

3.2 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 service users (24%), closely followed by the 'Existing service users' group (23.9%) the 'Discharge' group (22.4%) and the 'New referrals' group (21.6%).

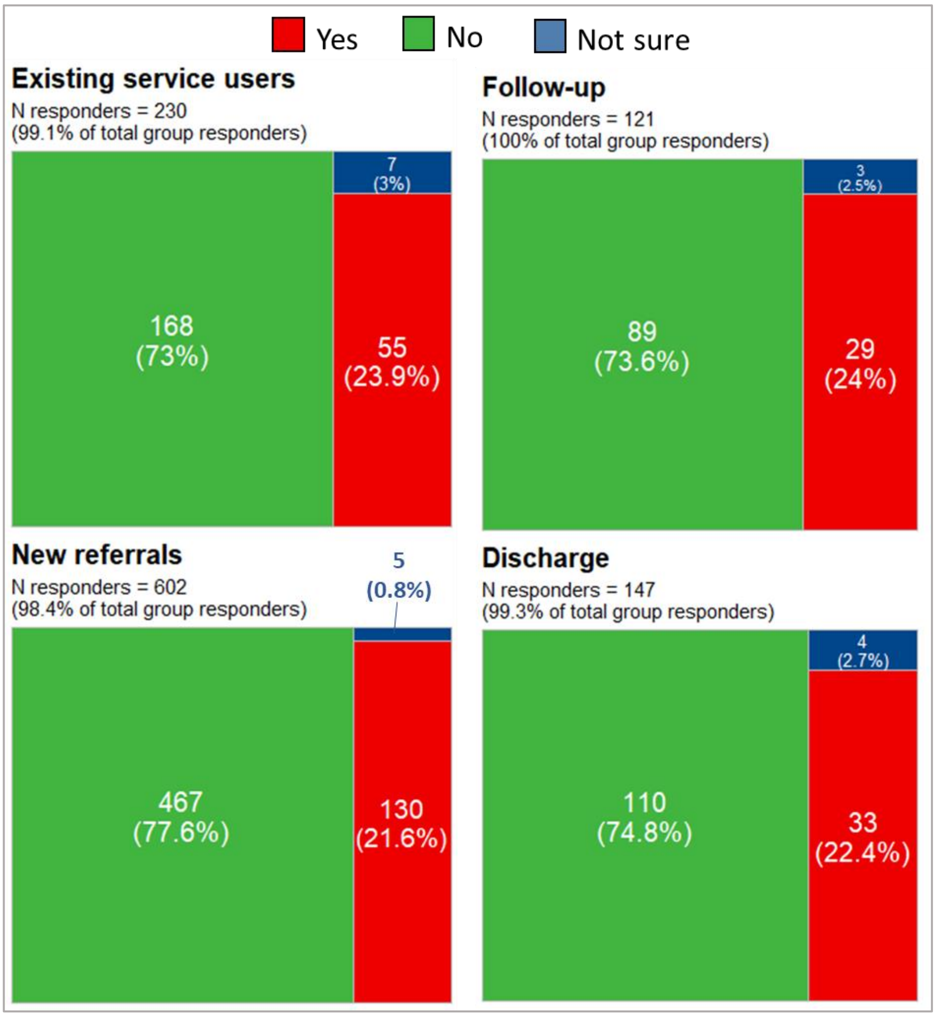


Figure 4. Tree map plots for: [Q5] ***"Have you been admitted to hospital as an in-patient as a result of COVID-19?"*** The numbers in the coloured areas indicate number of responders and percentage for each answer option within each service user group. (% of responses by LHB - AB UHB: 4.1%; BC UHB: 6.4%; CAV UHB: 17.8%; CTM UHB: 41.6%; HD UHB: 15.4%; PT HB: 2.8%; SB UHB: 11.9%)

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 20 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	121	29	27
% who answered the question	23.30%	19.80%	24%	18.20%
Minimum value	0	0	1	1
Median (IQR)	8 (5,21)	6 (2,14)	8 (3,30)	20 (7,74.5)
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: 5.2%; BC UHB: 5.2%; CAV UHB: 19%; CTM UHB: 40.3%; HD UHB: 15.2%; PT HB: 1.7%; SB UHB: 13.4%)

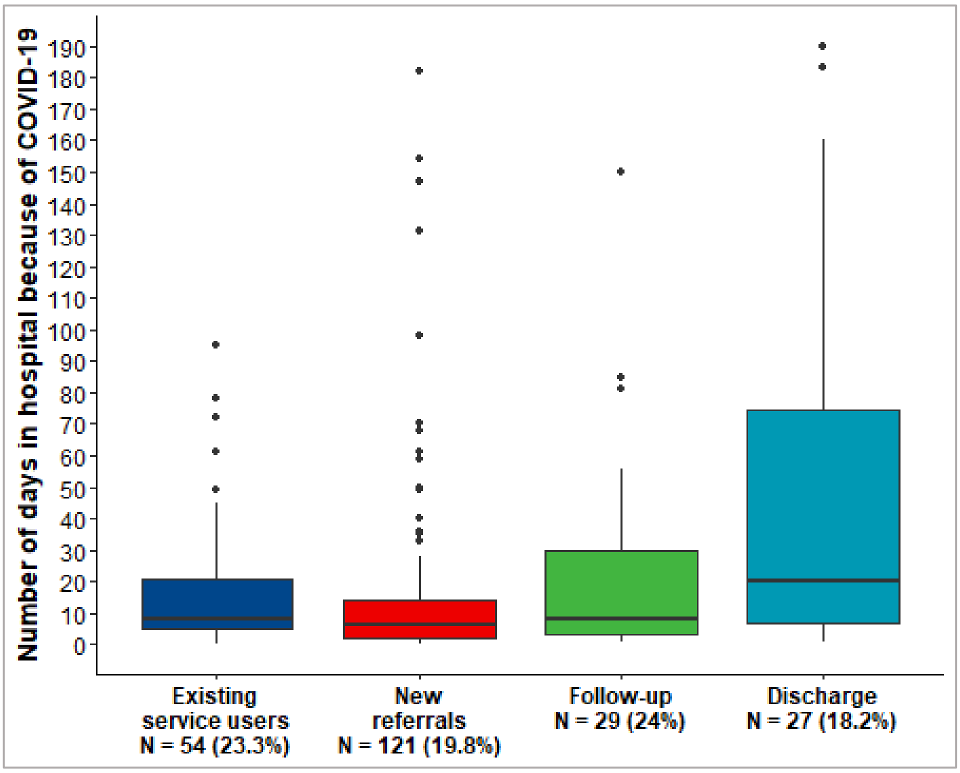


Figure 5. Box plots for [**Q5a**]: *(If you answered 'Yes' to Q5)* ***In total, how many days did you spend in hospital because of COVID-19?*** *(If you are still in hospital, please tell us how many days you have been in hospital so far).* For each service user group, number of responders (N) and the % of total group responders are reported under the group label. (% of responses by LHB - AB UHB: 5.2%; BC UHB: 5.2%; CAV UHB: 19%; CTM UHB: 40.3%; HD UHB: 15.2%; PT HB: 1.7%; SB UHB: 13.4%)

3.3 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': 88.4%, 'Follow-up': 85.1% and 'Discharge': 69.6%). Other frequent symptoms (experiences by more than 50% of responders) were '*Shortness of breath*', '*Brain fog*', '*Joint pain*', '*Insomnia*' and '*Depression and anxiety*'.

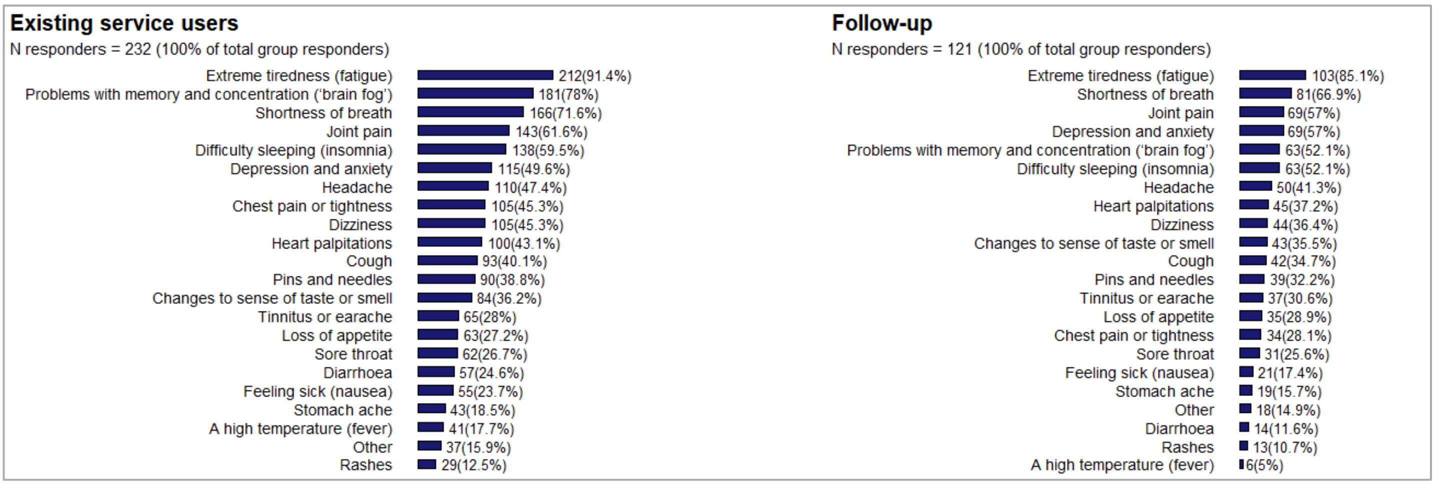


Figure 6. Bar plots for [Q6]: *"Please tell us about any symptoms you have experienced today due to COVID-19".* Data for 'Existing service users' and 'Follow-up' service user groups. Multiple responses per participant were allowed for this question (i.e., for each bar, 100% would represent that all responders within the group chose that option). (% of responses by LHB - AB UHB: 4%; BC UHB: 6.7%; CAV UHB: 17.8%; CTM UHB: 41.7%; HD UHB: 15.2%; PT HB: 2.8%; SB UHB: 11.8%).

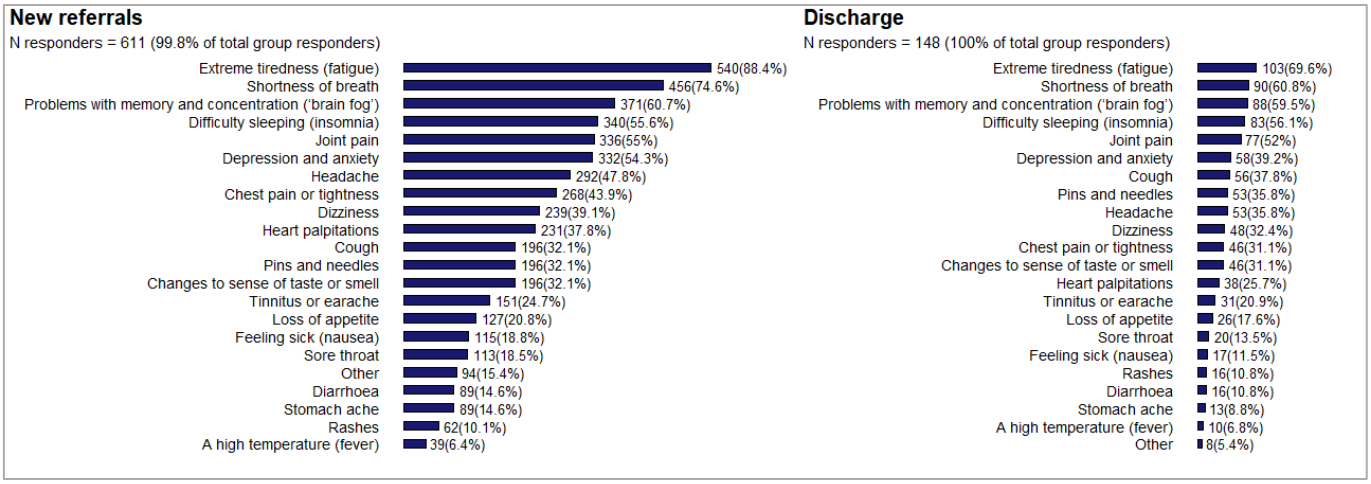


Figure 7. Bar plots for [Q6]: *"Please tell us about any symptoms you have experienced today due to COVID-19".* Data for 'New referrals' and 'Discharge' service user groups. Multiple responses per participant were allowed for this question (i.e., for each bar, 100% would represent that all responders within the group chose that option). (% of responses by LHB - AB UHB: 4%; BC UHB: 6.7%; CAV UHB: 17.8%; CTM UHB: 41.7%; HD UHB: 15.2%; PT HB: 2.8%; SB UHB: 11.8%).

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 and reported by 185 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 = 89 (14.5%)	Follow-up N = 17 (14%)	Discharge N = 8 (5.4%)
Pain (e.g muscle pain/stiffness, general or localised pain in the body)	8 (21.6%)	27 (30.3%)	5 (29.4%)	2 (25%)
Voice, mouth, throat and swallowing issues	3 (8.1%)	14 (15.7%)	7 (41.2%)	1 (12.5%)
Mobility issues (including leg issues, balance issues)	6 (16.2%)	13 (14.6%)	0 (0%)	2 (25%)
Vision and eye issues	8 (21.6%)	8 (9%)	3 (17.6%)	1 (12.5%)
Excessive sweating/feeling hot and/or inability to regulate body temperature	3 (8.1%)	10 (11.2%)	1 (5.9%)	1 (12.5%)
Hair loss	4 (10.8%)	5 (6%)	0 (0%)	0 (0%)
Bladder issues (e.g. inflammation and incontinence)	1 (2.7%)	4 (4.5%)	1 (5.9%)	1 (12.5%)
Issues with limb extremities (cold, sore, itching, swelling)	2 (5.4%)	3 (3.4%)	1 (5.9%)	0 (0%)
Hypersensitivity (e.g. to light, sound, pain or skin hypersensitivity)	2 (5.4%)	3 (3.4%)	1 (5.9%)	0 (0%)
Nose and/or sinus issues (e.g. nose bleed, nasal inflammation, sinus congestion)	2 (5.4%)	2 (2.2%)	2 (11.8%)	0 (0%)
Speech production or understanding issues	1 (2.7%)	2 (2.2%)	2 (11.8%)	0 (0%)
Cardiovascular issues (e.g. tachycardia)	3 (8.1%)	1 (1.1%)	0 (0%)	0 (0%)
Gastrointestinal issues	1 (2.7%)	2 (2.2%)	1 (5.9%)	0 (0%)
Involuntary tremor	0 (0%)	4 (4.5%)	0 (0%)	0 (0%)
Post-exertional malaise	0 (0%)	2 (2.2%)	2 (11.8%)	0 (0%)
Reflux, heartburn	2 (5.4%)	2 (2.2%)	0 (0%)	0 (0%)
Deconditioning	0 (0%)	3 (3.4%)	0 (0%)	0 (0%)
Dysautonomia issues/Postural Orthostatic Tachycardia Syndrome (POTS)/ Orthostatic Intolerance	0 (0%)	2 (2.2%)	1 (5.9%)	0 (0%)
Hearing loss	1 (2.7%)	1 (1.1%)	0 (0%)	1 (12.5%)
Weight issue, either gain or loss	0 (0%)	2 (2.2%)	0 (0%)	1 (12.5%)
Falling	1 (2.7%)	0 (0%)	1 (5.9%)	0 (0%)
Swollen glands	0 (0%)	1 (1.1%)	1 (5.9%)	0 (0%)
Hyperventilating as a result of exposure to fresh air / Bronchial hyperactivity	0 (0%)	1 (1.1%)	1 (5.9%)	0 (0%)
Lower immunity (e.g. increase rate of chest infections)	1 (2.7%)	1 (1.1%)	0 (0%)	0 (0%)
Lung issues	0 (0%)	2 (2.2%)	0 (0%)	0 (0%)
Menstrual issues	1 (2.7%)	1 (1.1%)	0 (0%)	0 (0%)
Numbness of body (e.g. feet, face)	2 (5.4%)	0 (0%)	0 (0%)	0 (0%)

Panic attacks	0 (0%)	2 (2.2%)	0 (0%)	0 (0%)
Phlegm at night	1 (2.7%)	1 (1.1%)	0 (0%)	0 (0%)
Vivid dreams, nightmares, waking up sharp with anxiety	0 (0%)	2 (2.2%)	0 (0%)	0 (0%)
Vertigo	1 (2.7%)	0 (0%)	1 (5.9%)	0 (0%)
Allergy, MCAS (Mast Cell Activation Syndrome)	0 (0%)	0 (0%)	0 (0%)	1 (12.5%)
Arthritis	0 (0%)	0 (0%)	1 (5.9%)	0 (0%)
Hiatus hernia	0 (0%)	1 (1.1%)	0 (0%)	0 (0%)
Inflammation	0 (0%)	1 (1.1%)	0 (0%)	0 (0%)
Mood issues (e.g. extreme mood swings, low mood)	0 (0%)	1 (1.1%)	0 (0%)	0 (0%)
Post-Traumatic Stress Disorder	0 (0%)	1 (1.1%)	0 (0%)	0 (0%)
Shingles	1 (2.7%)	0 (0%)	0 (0%)	0 (0%)
Excessive thirst	1 (2.7%)	0 (0%)	0 (0%)	0 (0%)

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

3.4 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	597	115	138
% who answered the question	97%	97.50%	95%	93.20%
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: 4.1%; BC UHB: 6.6%; CAV UHB: 17.8%; CTM UHB: 42%; HD UHB: 14.9%; PT HB: 2.8%; SB UHB: 11.9%).

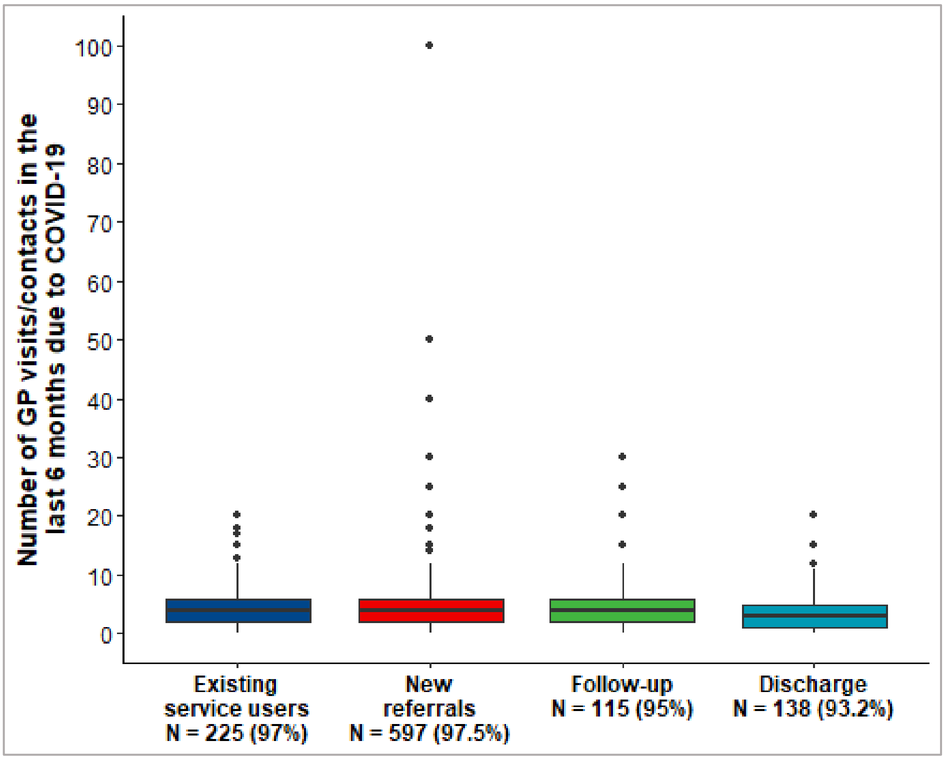


Figure 8. Box plots for: [Q7] *"Please tell us how many GP visits/contacts (face-to-face or remotely) you have had in the last 6 months related to COVID-19".* For each service user group, number of responders (N) and the % of total group responders are reported under the group label. (% of responses by LHB - AB UHB: 4.1%; BC UHB: 6.6%; CAV UHB: 17.8%; CTM UHB: 42%; HD UHB: 14.9%; PT HB: 2.8%; SB UHB: 11.9%).

3.5 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	471	100	136
% who answered the question	84.10%	77%	82.60%	91.90%
Minimum value	0	0	0	0
Median (IQR)	3 (1,6)	1 (0,1)	5 (3,8)	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: 3.5%; BC UHB: 5.7%; CAV UHB: 15.2%; CTM UHB: 48.8%; HD UHB: 13.6%; PT HB: 2.7%; SB UHB: 10.5%).

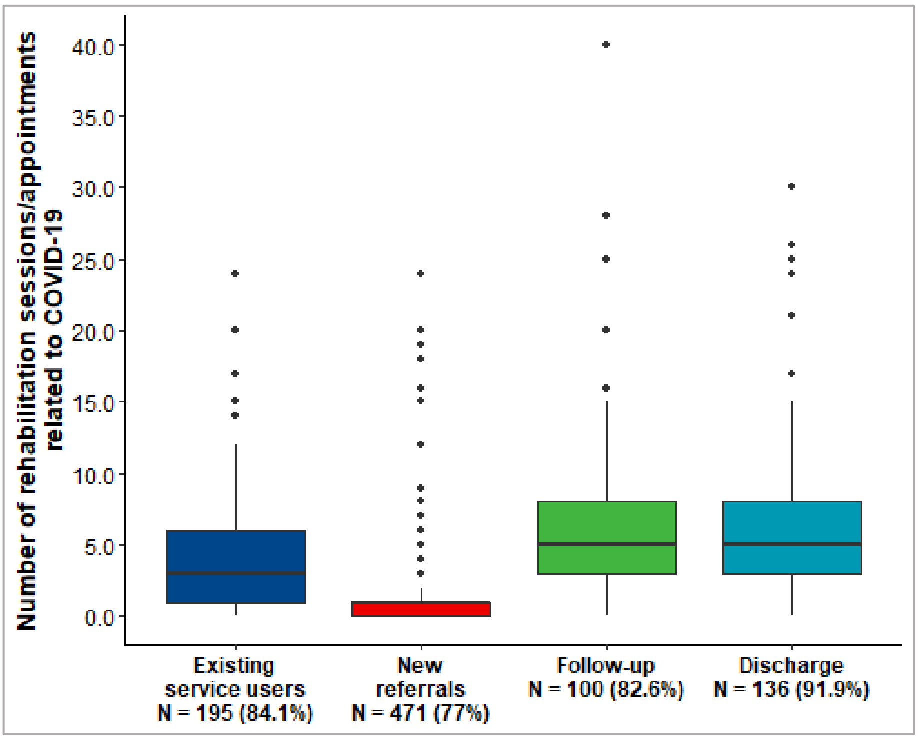


Figure 9. Box plots for: [Q8] *"If you have had rehabilitation related to your COVID-19, please tell us how many sessions/appointments you have had".* For each service user group, number of responders (N) and the % of total group responders are reported under the group label. (% of responses by LHB - AB UHB: 3.5%; BC UHB: 5.7%; CAV UHB: 15.2%; CTM UHB: 48.8%; HD UHB: 13.6%; PT HB: 2.7%; SB UHB: 10.5%).

3.6 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 (32.1%): '*I have moderate problems in walking about'* (score 3)
- For the 'Follow-up' group (31.4%): '*I have no problems in walking about*' (score 1)
- For the 'Discharge' group (39.2%): '*I have no problems in walking about*' (score 1)

In all groups, < 1% of responders chose the most severe option (score 5) '*I am unable to walk about*'.

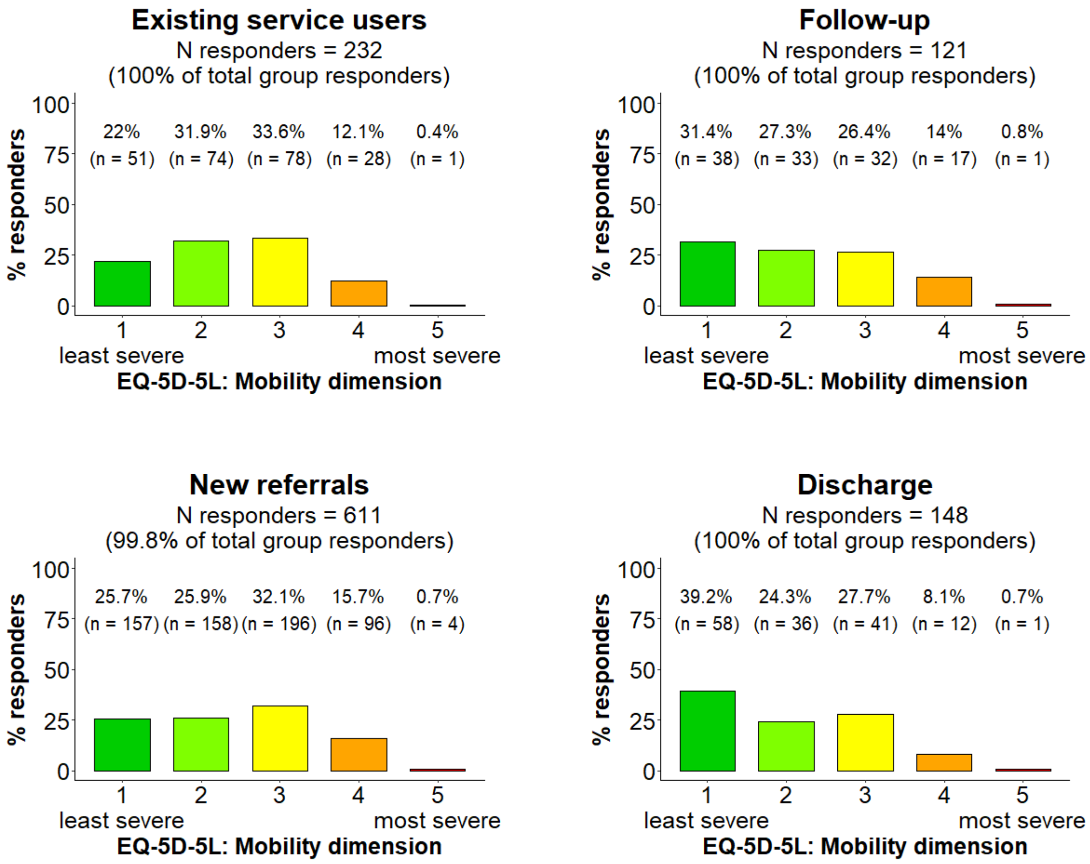


Figure 10. % Bar plots for: [Q9] *"Please select the option that best describes your health TODAY: MOBILITY"*. N = number of responders for each service user group. n = number of group responders that chose the specific EQ-5D-5L dimension score. (% of responses by LHB - AB UHB: 4%; BC UHB: 6.7%; CAV UHB: 17.8%; CTM UHB: 41.7%; HD UHB: 15.2%; PT HB: 2.8%; SB UHB: 11.8%).

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 (52.9%): '*I have no problems washing or dressing myself*' (score 1)
- For the 'Discharge' group (66.2%): '*I have no problems washing or dressing myself*' (score 1)

In all groups, < 1% of responders chose the most severe option (score 5) '*I am unable to wash or dress myself*'.

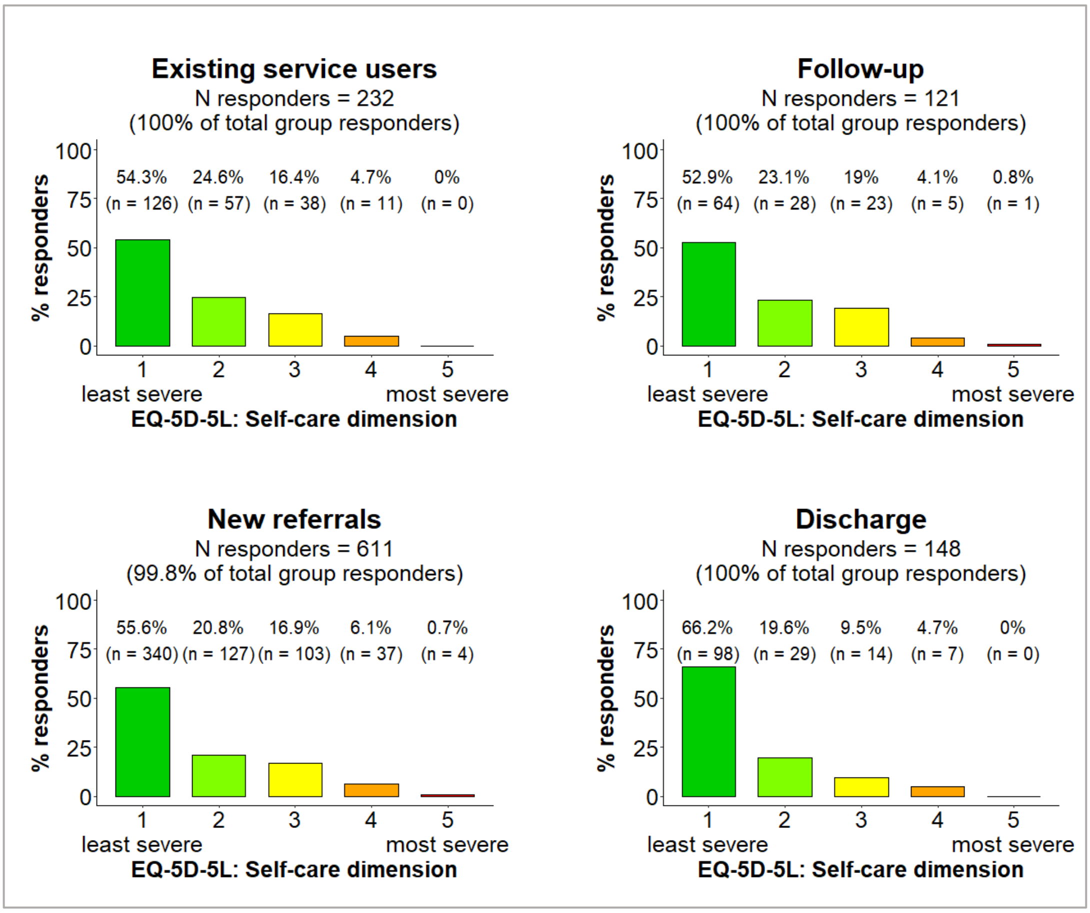


Figure 11. % Bar plots for: [Q10] "*Please select the option that best describes your health TODAY: SELF-CARE*". N = number of responders for each service user group. n = number of group responders that chose the specific EQ-5D-5L dimension score. (% of responses by LHB - AB UHB: 4%; BC UHB: 6.7%; CAV UHB: 17.8%; CTM UHB: 41.7%; HD UHB: 15.2%; PT HB: 2.8%; SB UHB: 11.8%).

<u>EQ-5D-5L dimension: ‘Usual activities’</u> (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 (34.4%): ‘*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 (31.1%): *I have moderate problems doing my usual activities*’ (score 3)

In all groups, 8.8-14.7% of responders chose the most severe option (score 5) ‘*I am unable to do my usual activities*’ (‘New referrals’: 14.7%; ‘Follow-up’: 13.2%; ‘Existing service users’: 9.1%; ‘Discharge’: 8.8%).

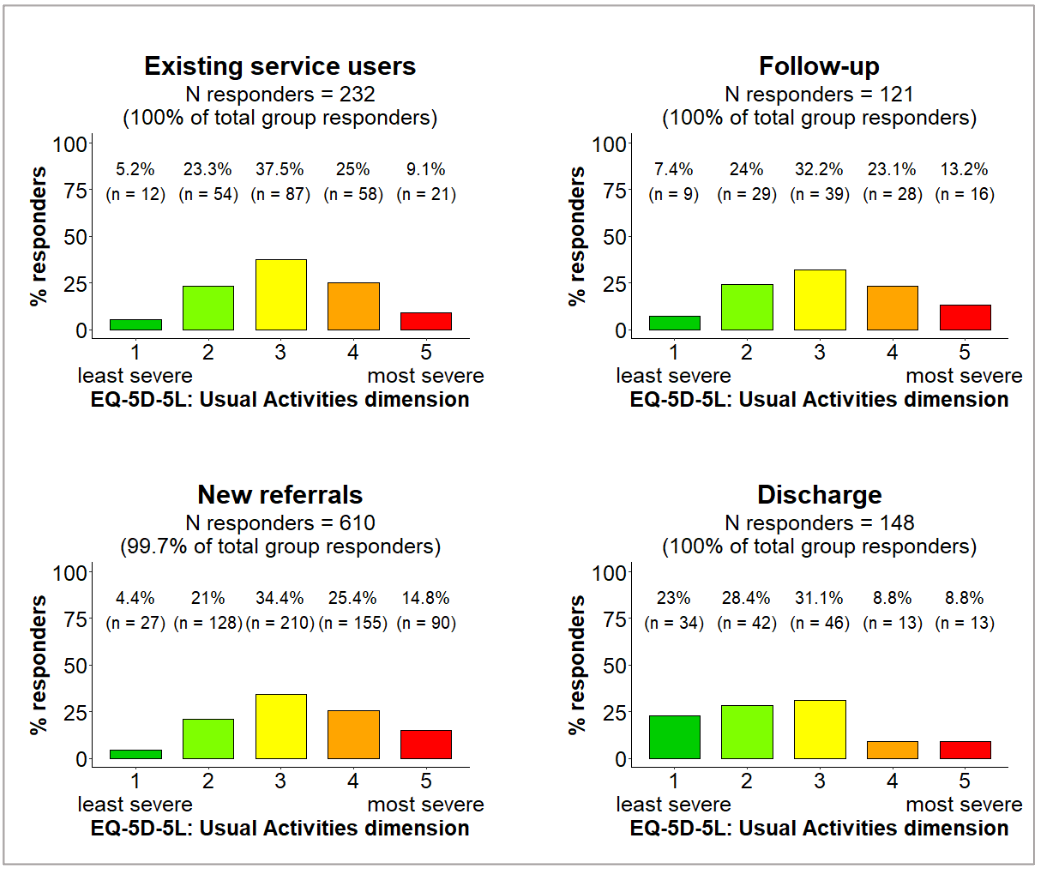


Figure 12. % Bar plots for: [Q11] “*Please select the option that best describes your health TODAY: USUAL ACTIVITIES*”. N = number of responders for each service user group. n = number of group responders that chose the specific EQ-5D-5L dimension score. (% of responses by LHB - AB UHB: 4.1%; BC UHB: 6.7%; CAV UHB: 17.8%; CTM UHB: 41.8%; HD UHB: 15.1%; PT HB: 2.8%; SB UHB: 11.8%).

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 (36.2%): '*I have moderate pain or discomfort*' (score 3)
- For the 'Follow-up' group (38.8%): '*I have moderate pain or discomfort*' (score 3)
- For the 'Discharge' group (29.1%): '*I have slight pain or discomfort''* (score 2)

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

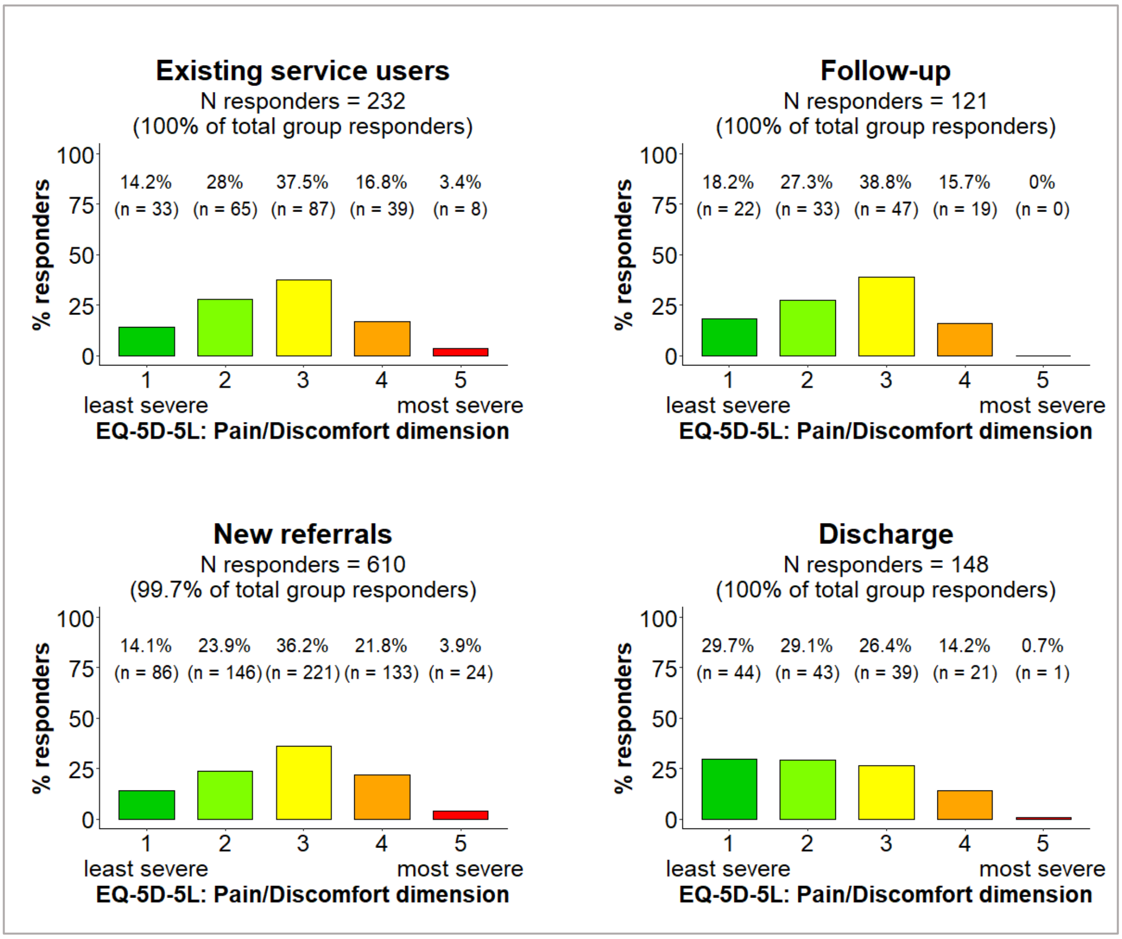


Figure 13. % Bar plots for: [Q12] "*Please select the option that best describes your health TODAY: PAIN & DISCOMFORT*". N = number of responders for each service user group. n = number of group responders that chose the specific EQ-5D-5L dimension score. (% of responses by LHB - AB UHB: 4.1%; BC UHB: 6.7%; CAV UHB: 17.8%; CTM UHB: 41.8%; HD UHB: 15.1%; PT HB: 2.8%; SB UHB: 11.8%).

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 (33.8%): '*I am moderately anxious or depressed*' (score 3)
- For the 'Follow-up' group (34.7%): '*I am slightly anxious or depressed*' (score 2)
- For the 'Discharge' group (39.2%): '*I am not anxious or depressed*' (score 1)

In all groups, < 6% of responders chose the most severe option (score 5) '*I am extremely anxious or depressed*'.

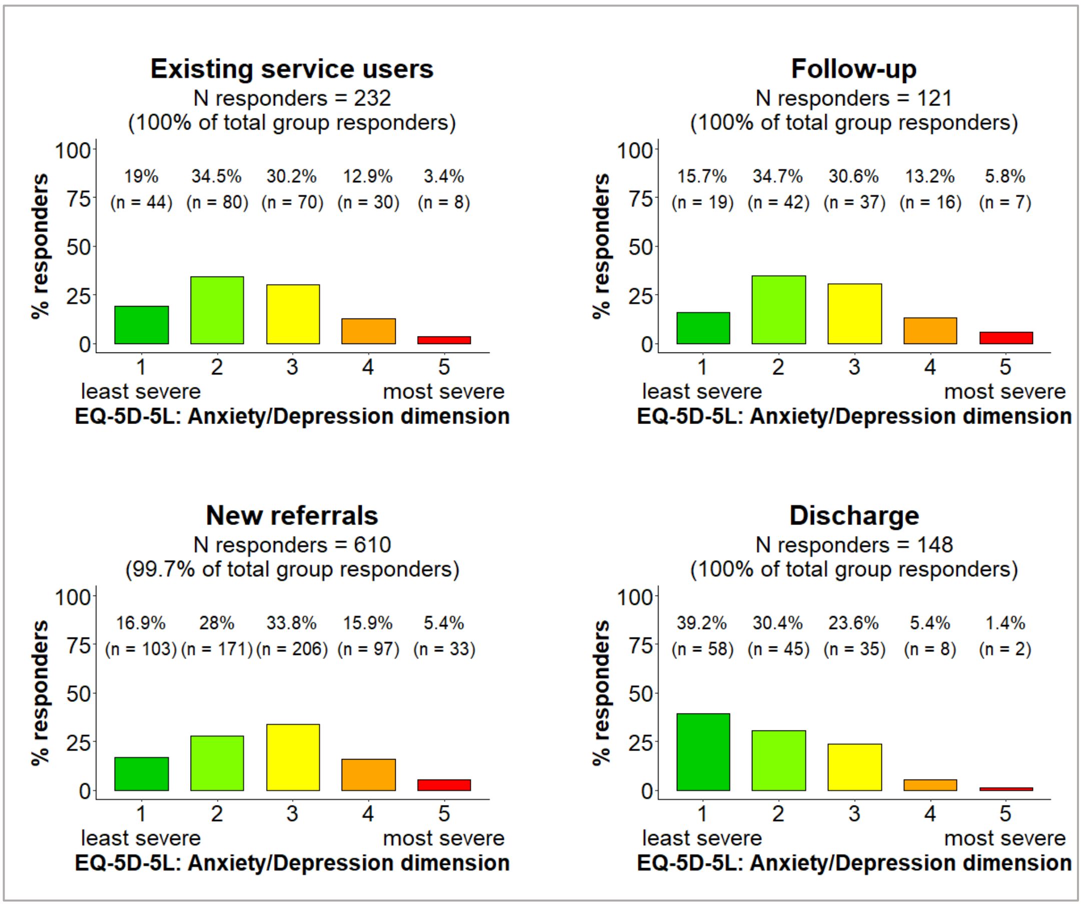


Figure 14. % Bar plots for: [Q13] *"Please select the option that best describes your health TODAY: ANXIETY & DEPRESSION"*. N = number of responders for each service user group. n = number of group responders that chose the specific EQ-5D-5L dimension score. (% of responses by LHB - AB UHB: 4.1%; BC UHB: 6.7%; CAV UHB: 17.8%; CTM UHB: 41.8%; HD UHB: 15.1%; PT HB: 2.8%; SB UHB: 11.8%).

The EQ-5D-5L index was calculated for each responder by combining their EQ-5D-5L dimension scores (see Methods section 2.1.1). Results are reported in Table 8 and in Figure 15. The 'Discharge' group had the highest median EQ-5D-5L index (0.69), while the 'New referrals' group had the lowest (0.53).

The statistical distributions of EQ-5D-5L index were significantly different across the four service user cohorts (Kruskal-Wallis test: H (3) = 45.4, p < 0.001). Those in the 'Discharge' group tended to have a 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 < 0.01).

	Existing service users	New referrals	Follow-up	Discharge
Number of responders	232	610	121	148
% for whom EQ-5D-5L Index was calculated	100%	99.70%	100%	100%
Minimum value	-0.283	-0.367	-0.248	-0.104
Median (IQR)	0.54 (0.3,0.7)	0.53 (0.2,0.7)	0.56 (0.3,0.7)	0.69 (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: 4.1%; BC UHB: 6.7%; CAV UHB: 17.8%; CTM UHB: 41.8%; HD UHB: 15.1%; PT HB: 2.8%; SB UHB: 11.8%).

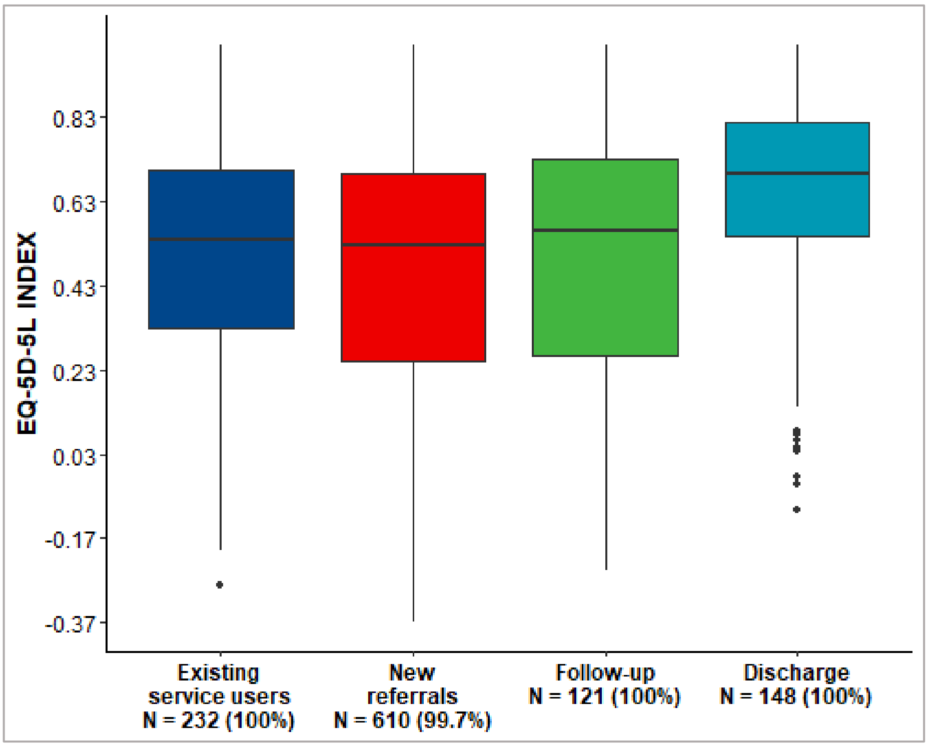


Figure 15. Box plots for: EQ-5D-5L index. Calculated from EQ-5D-5L scores [Q9]-[Q13]. For each service user group, number of responders (N) and the % of total group responders are reported under the group label. (% of responses by LHB - AB UHB: 4.1%; BC UHB: 6.7%; CAV UHB: 17.8%; CTM UHB: 41.8%; HD UHB: 15.1%; PT HB: 2.8%; SB UHB: 11.8%).

EQ-VAS results are reported for each group in Table 9 and Figure 16. The highest median EQ-VAS score was the one of the 'Discharge' group (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) = 62.9, p < 0.001). Those in the 'Discharge' group tended to have a 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).

	Existing service users	New referrals	Follow-up	Discharge
Number of responders	232	6910	120	147
% who answered the question	100%	99.70%	99.20%	99.30%
Minimum value	0	0	0	5
Median (IQR)	50 (40,70)	50 (30,65)	50 (39.2,70)	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: 4.1%; BC UHB: 6.7%; CAV UHB: 17.9%; CTM UHB: 41.8%; HD UHB: 15%; PT HB: 2.8%; SB UHB: 11.8%).

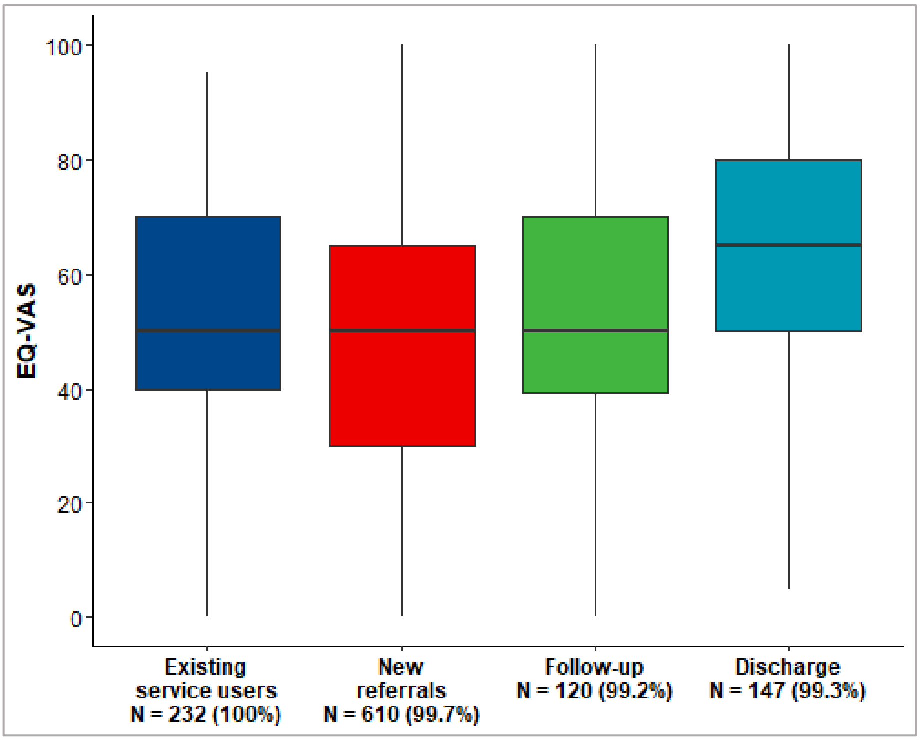


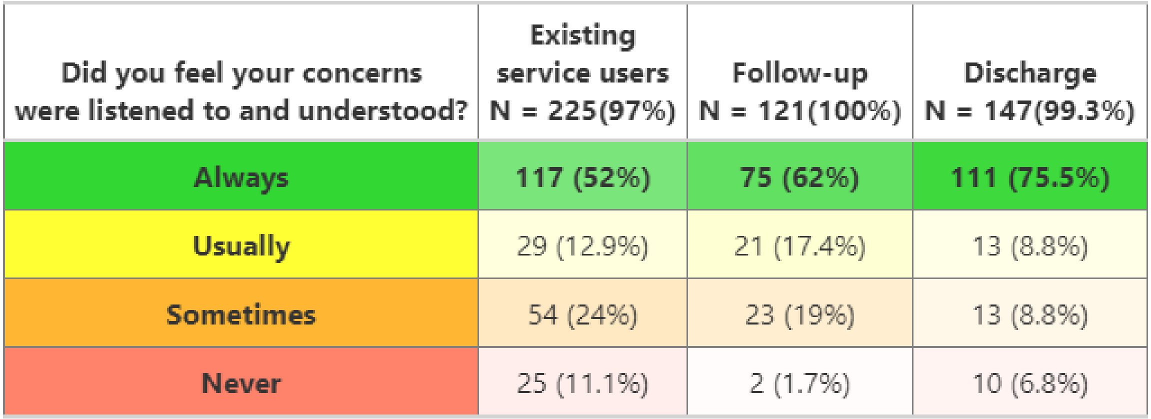
Figure 16. Box plots for: [Q14] "*We would like to know how good or bad your health is today (scale 0-100)*". For each service user group, number of responders (N) and the % of total group responders are reported under the group label. (% of responses by LHB - AB UHB: 4.1%; BC UHB: 6.7%; CAV UHB: 17.9%; CTM UHB: 41.8%; HD UHB: 15%; PT HB: 2.8%; SB UHB: 11.8%).

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

Responders were asked about their experiences with the Long COVID service. No responses were 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/understood, being supported in get the information needed and being involved in the support received), the majority of responders from all groups considered ('Existing service users', 'Follow-up' and 'Discharge' groups) appeared satisfied with the support they received.

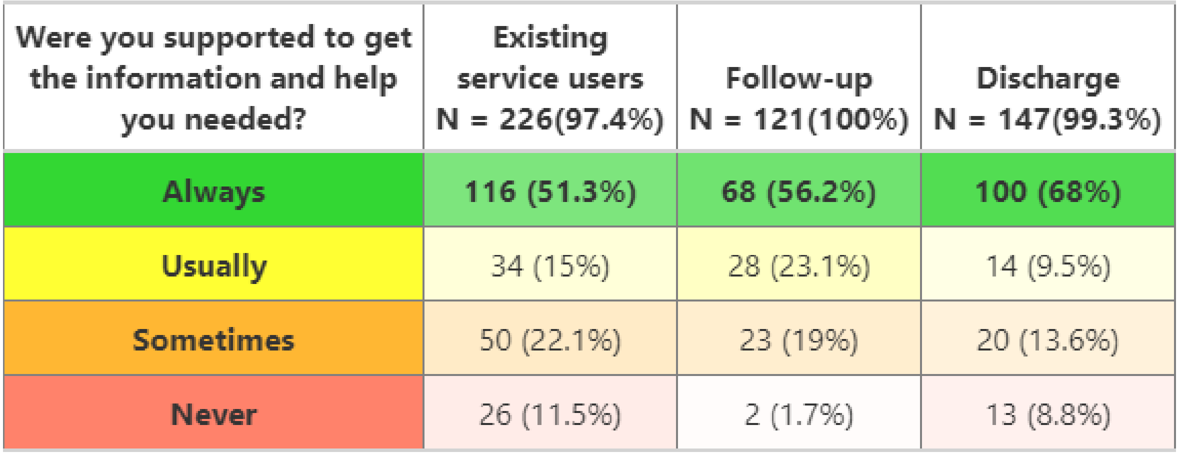
<u>PREM: 'Did you feel your concerns were listened to and understood?'</u> (Table 10). Most of the responders chose '*Always*' ('Discharge': 75.5%; 'Follow-up': 62% and 'Existing service users': 52%). The second most selected option was '*Sometimes*' ('Existing service users': 24%; 'Follow-up': 19%; 'Discharge': 8.8%) or '*Usually*' ('Discharge': 8.8%).



Did you feel your concerns were listened to and understood?	Existing service users N = 225(97%)	Follow-up N = 121(100%)	Discharge N = 147(99.3%)
Always	**117 (52%)**	**75 (62%)**	**111 (75.5%)**
Usually	29 (12.9%)	21 (17.4%)	13 (8.8%)
Sometimes	54 (24%)	23 (19%)	13 (8.8%)
Never	25 (11.1%)	2 (1.7%)	10 (6.8%)

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: 5.2%; BC UHB: 1.4%; CAV UHB: 21.5%; CTM UHB: 42.3%; HD UHB: 12.3%; PT HB: 4.4%; SB UHB: 12.9%).

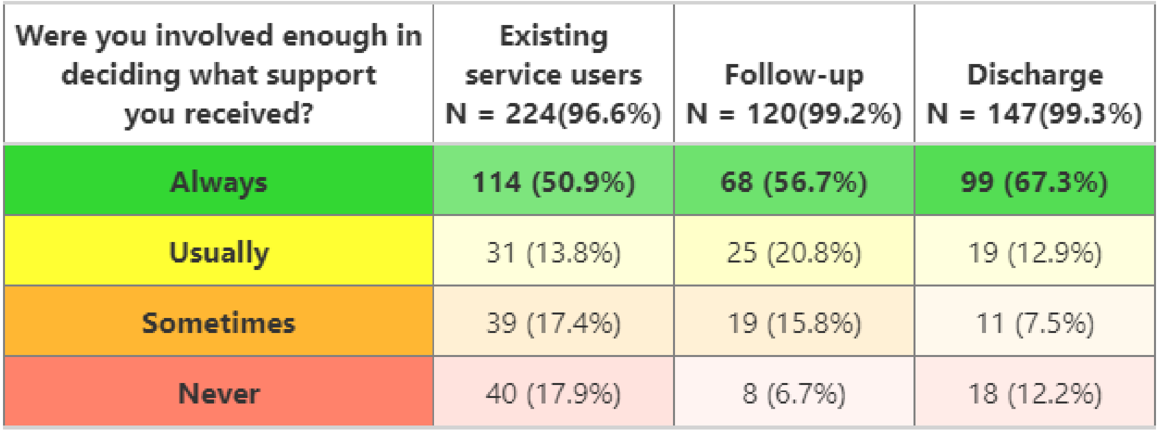
PREM: 'Were you supported to get the information and help you needed?' (Table 11). The majority of the responders in all groups chose '*Always*' ('Discharge': 68%; 'Follow-up': 56.2% and 'Existing service users': 51.3%). The second most selected option was either '*Sometimes*' ('Existing service users': 22.6%; 'Discharge': 21.1%) or '*Usually*' ('Follow-up': 18.8%).



Were you supported to get the information and help you needed?	Existing service users N = 226(97.4%)	Follow-up N = 121(100%)	Discharge N = 147(99.3%)
Always	**116 (51.3%)**	**68 (56.2%)**	**100 (68%)**
Usually	34 (15%)	28 (23.1%)	14 (9.5%)
Sometimes	50 (22.1%)	23 (19%)	20 (13.6%)
Never	26 (11.5%)	2 (1.7%)	13 (8.8%)

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: 5.2%; BC UHB: 1.4%; CAV UHB: 21.5%; CTM UHB: 42.2%; HD UHB: 12.2%; PT HB: 4.4%; SB UHB: 13.1%).

PREM: ‘Were you involved enough in deciding what support you received?’ (Table 12). The most frequent answer option in all groups was ‘*Always*’ (‘Discharge’: 67.3%; ‘Follow-up’: 56.7%; ‘Existing service users’: 50.9%). The next most frequent answer was ‘*Usually*’ for ‘Follow-up’ (20.8%) and ‘Discharge’ (12.9%), and ‘*Never*’ for the ‘Existing service users’ (17.9%).

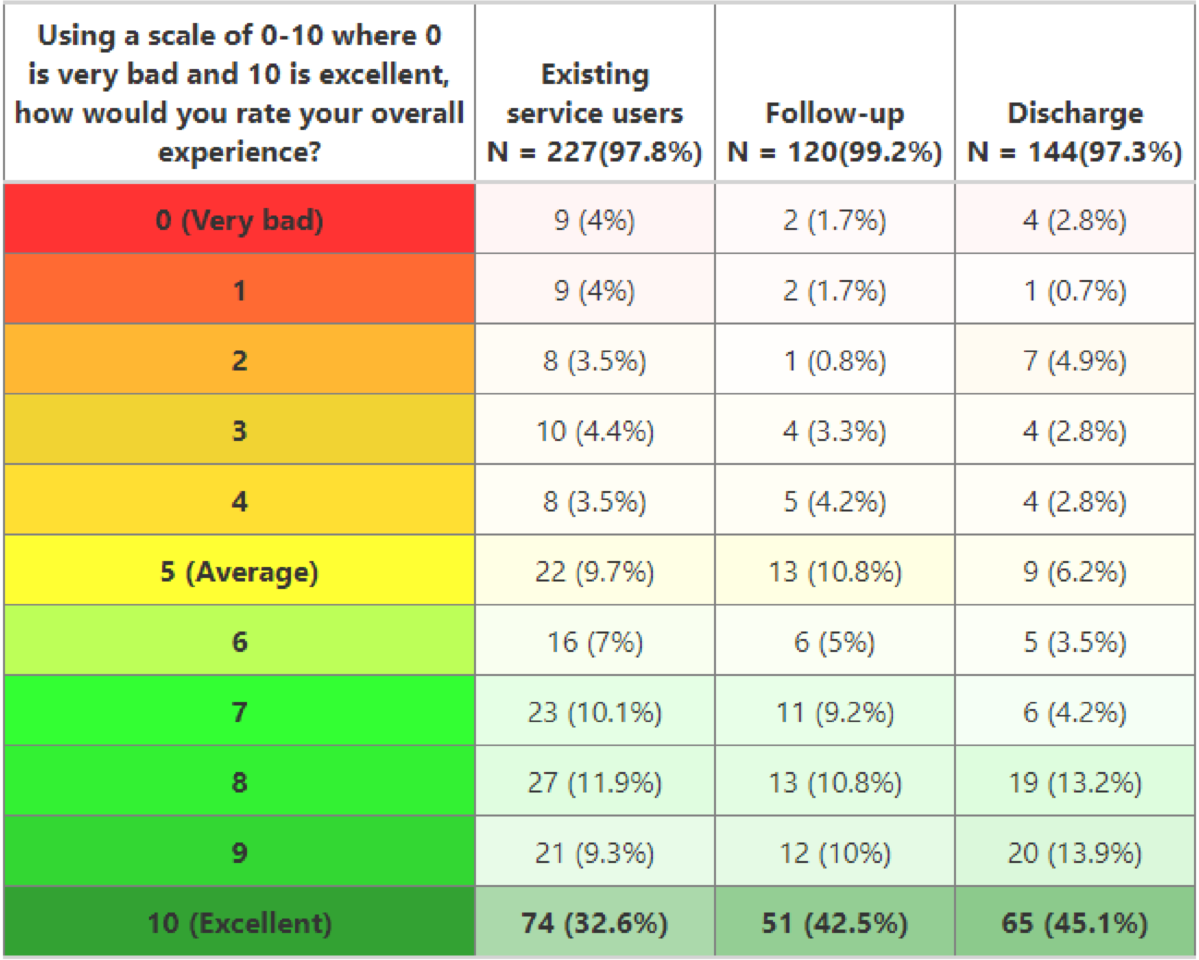


Were you involved enough in deciding what support you received?	Existing service users N = 224(96.6%)	Follow-up N = 120(99.2%)	Discharge N = 147(99.3%)
Always	**114 (50.9%)**	**68 (56.7%)**	**99 (67.3%)**
Usually	31 (13.8%)	25 (20.8%)	19 (12.9%)
Sometimes	39 (17.4%)	19 (15.8%)	11 (7.5%)
Never	40 (17.9%)	8 (6.7%)	18 (12.2%)

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: 5.3%; BC UHB: 1.4%; CAV UHB: 21.2%; CTM UHB: 42.4%; HD UHB: 12.3%; PT HB: 4.4%; SB UHB: 12.9%).

Considering their overall 'Long COVID service experience' (Table 13), more than 70% of the responders selected an above average rate (>5): 79.9% of 'Discharge', 77.5% of 'Follow-up' and 70.9% of 'Existing service users'. In all groups, the highest proportion chose the maximum rate of 10 ('*Excellent*').

At the other end of the rating scale, 19.4% of 'Existing service users', 13.9% of 'Discharge' and 11.7% of 'Follow-up' 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 = 120(99.2%)	Discharge N = 144(97.3%)
0 (Very bad)	9 (4%)	2 (1.7%)	4 (2.8%)
1	9 (4%)	2 (1.7%)	1 (0.7%)
2	8 (3.5%)	1 (0.8%)	7 (4.9%)
3	10 (4.4%)	4 (3.3%)	4 (2.8%)
4	8 (3.5%)	5 (4.2%)	4 (2.8%)
5 (Average)	22 (9.7%)	13 (10.8%)	9 (6.2%)
6	16 (7%)	6 (5%)	5 (3.5%)
7	23 (10.1%)	11 (9.2%)	6 (4.2%)
8	27 (11.9%)	13 (10.8%)	19 (13.2%)
9	21 (9.3%)	12 (10%)	20 (13.9%)
10 (Excellent)	**74 (32.6%)**	**51 (42.5%)**	**65 (45.1%)**

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: 5.3%; BC UHB: 1.4%; CAV UHB: 21.6%; CTM UHB: 42%; HD UHB: 11.9%; PT HB: 4.4%; SB UHB: 13.3%).

A total of 174 responders provided further feedback in regards of their service experiences via free text (responses collected between the 1st of January 2022 to the 31st of March 2022; see Appendices 3-6 for thematic analysis of previous responses). Results were summarised by identifying core themes and representative quotes: Table 14 contains positive feedback, Table 15 and Table 16 contain negative feedback (specific for the service or not, respectively) and Table 17 contains suggestions for improvement.

Many responders expressed their gratitude to the Long COVID service for feeling listened to and acknowledged, having received helpful treatment and advice and been put in touch with other fellow sufferers who can understand what they are going through (Table 14). However, other responders (Table 15) urged the service to become more tailored around different users' needs. They suggested the service should expand beyond rehabilitation support/symptom management and develop tighter links with medical consultants, since this would allow prompt medical testing and diagnosis to inform treatment. Some responders would prefer more face-to-face appointments, now that rules allow, and longer/more frequent sessions. Keeping service users up-to-date with research developments in Long COVID treatment was mentioned as beneficial (Table 17).

Themes (Positive feedback)	**Existing service users N = 6**	**Follow-up N = 71**	**Discharge N = 97**
Excellent support from the Long COVID service • *"The support and understanding and patience was amazing"* • ***"T**he team have been quick in responding with emails and sending out information. Excellent communication […] I have recommended service to a friend and I have told my manager about the service so hopefully it will spread awareness."* • *"It's a very good service"* • *"Great follow up sessions."* • *"Positive experience, been great having somebody to understand and reassure. Thank you. You should be applauded for your service and for all that you are going."* • *"Can't thank you enough. It's good to know someone cares"* • *"Help provided has been amazing due to new Long COVID. Knowing able to email and contact. accessibility of service has been fantastic"* • *"The experience has been outstanding, I would like to thank you all. You called me on a down day and picked me back up."* • *"Good communication and flexible service"* • *"I think the Long COVID team/service should be commended."* • *"It's a service that's very much needed."*	1	12	35
Responders felt put at ease, listened to and acknowledged by the Long COVID team • *"Having support knowing not on my own and someone to advise and support recovery"* • *"They had time to listen and I felt fully supported by their suggestions and the help offered."*	1	39	46

• *“I have felt completely valued, listened to, consulted about and in control of my recovery.”* • *“To find that the staff were open, friendly, understanding, patient, empathetic, knowledgeable and supportive was immensely helpful. To feel that someone understands and supports you and reassures you that this is not all in your head and is real and knows how that COVID 19 can be very debilitating, is so reassuring and helps you both physically and mentally.”* • *“Friendly, supportive staff, empathetic and listening to my concerns. Thank you!”* • *“I always felt someone was there to listen to me, I didn't feel ignored.”* • *“I feel wonderful talking to you, I feel at ease and look forward to when you call.”* • *“The team were very accommodating, very understanding, caring and they listened to me.”* • *“The staff are very nice and are trying to help. They were amongst the first to actually listen to my experience and I am very grateful to them.”* • *“The Long COVID team have been extremely understanding and it’s been very helpful having someone to talk to about my symptoms who does not make me feel like a hypochondriac “* • *“The service staff were the first NHS staff who listened and empathised with my experience of Long COVID.”* • *“I was finally listened to, someone believed in me. To be able to talk to someone and go through plans for my rehabilitation, although there is no magic wand I feel that with help and support I will get through this.”*			
Responders found the Long COVID service staff knowledgeable and the advice/treatment provided helpful • *“I feel that this help and support has been invaluable to me and has given me so many strategies to help me cope with my ongoing symptoms.”* • *“It made a big difference to me, I feel better able to cope and feel better in terms of symptoms”* • *“you've always been brilliant and come up with good ideas of support. You have also chased everything up which has been helpful”* • *“Strategies to put in place useful”* • *“Emails were useful to follow up on information given, the exercises I found particularly useful”* • *“Through the Long COVID Service I have learned more about the condition.”* • *“They […] worked with me and enabled me to identify how I could constructively move forward supported by them and how I could best support myself. […] I am not cured, but I am in control - patient centred care and ownership by the patient/client. […] I have recommended this service to others including young people who are really struggling with Long COVID and related mental health issues.”* • *“Practical advice that facilitated some autonomy over the condition.”*	3	30	35
Responders mentioned specific components of the Long COVID service that improved their recovery • *“I have been given information, advice, physical, emotional and financial support from a wide range of services […] pain and fatigue clinic, respiratory services, speech and language therapists and Silvercloud supporters. Amazing!”* • *“Pulmonary rehabilitation for Long COVID was very good in helping me understand what was happening to my body and gave me tips on how to help myself.”*	1	14	13

• *“The session in sleep was particularly useful and I wish that had been longer.”* • *“The Rehab team physio who I had a 1:1 phone call assessment with was excellent.”* • *“Breathing exercise were good and memory aides helped.”* • *“[…] I found the activity dairies really useful also as it has helped me to monitor and self-manage better.”* • *“Help from the physio with moving and support with PTSD [Post-Traumatic Stress Disorder].”* • *“Having someone to talk through the difficulties with mental health issues. Physical activity from rehab – physiotherapy.”* • *“Very good support from occupational therapist when required.”* • *“Going on an EPP [Education Programs for Patients] course was invaluable”* • *“1-2-1 with psychologist”.* • *“Range of suggestions given by speech to manage symptoms”* • *“Oral spray for dry mouth from the speech therapists was helpful”* • *“Just having the support and advise about pacing was great, I just wish I could have had it 12 months earlier. “*			
Responders valued the group sessions, which allowed them to get mutual support, sharing and recognition from the interaction with other patients • *“Meeting others in the same boat was a huge positive.”* • *“The online group sessions with others who are going through the same thing are really helpful to give you the opportunity to share your problems with them and to gain and share tips and strategies from others who have been or are going through the same things.”* • *“Good to connect with others who had Long COVID.”* • *“Group zoom meetings - sharing information with other sufferers”*	1	6	4
Good support from GPs • *“The GP spent time to understand the problems, arrange tests to rule out other issues, tried different medications and then referral to the Long COVID rehab service.”* • *“The GP acted on suggestions given by the team, an appointment with another service was also arranged directly.”*	1	3	3
Responders felt the Long COVID service was personalised around their needs • *“I felt that the rehab on offer was based on what I needed.”* • *“Friendly, sympathetic medical staff who listened, understood and tried to cater for individual needs.”* • *“Individually tailored rehab”.* • *“It was helpful to discuss ongoing symptoms and receive personalised advice on current management.”*	0	3	1

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– specific for Long COVID service)	Existing service users N = 6	Follow-up N = 71	Discharge N = 97
The advice/treatment offered is too generic and not enough tailored around individual user's needs • *"Information provided by professionals to be more individual to service user."* • *"Course was solely about fatigue, much of which I had already researched and put into practice as I have suffered with LC for nearly 2years. It would be great if the remit was expanded to include the other main debilitating symptoms of LC."* • *"Help agreed was too general and not individualized"* • *"Sessions were almost all talking and slides not good with brain fog. Too much emphasis on getting back to work not getting us well."* • *"It doesn't differentiate different subtypes of LC. Not assessing for PEM [Protein-Energy Malnutrition] whilst prescribing exercise is potentially harmful practice"* • *"Only rehab and general info on health, diet and wellbeing. […] Only advice on how to live within my physical limits until I magically get better."* • *"I have marked the service down unfortunately because it is not the right service for me, and I believe many others. I am in contact with LC patient groups and many fellow LC patients are of the same opinion that it is not meeting their needs"*	0	9	9
More medical diagnosis and testing available to facilitate treatment, not just rehabilitation • *"Diagnosis is missing, putting rehab in without a diagnosis"* • *"This is not the right service for many of us with Long COVID. I need medical investigation and treatment. This has been nigh on impossible to get access to. The Long COVID service has no medical input, therefore cannot assess medical needs, and are not able to refer to secondary specialist services or for medical investigations, and cannot offer medical treatment […] This can only be addressed by Welsh government commissioning specialist consultant led Long COVID assessment and treatment centres."* • *"Consultant led clinics, with multi-disciplinary team who are able to discuss individual needs and provide assessments and treatment options in one place".* • *"[…] the service was offered instead of medical assessment, diagnosis and treatment, which is what I need. This has not been done by my GP, the Long COVID (LC) service has not been commissioned to do this and has no medical lead, and no MDT medical input, and no links to refer onwards to secondary care specialists where it is needed […] In England, LC services involve a medical assessment and access to specialist medics, which is often needed. It is unacceptable that in Wales there is no specialist medical input to LC clinics, and I believe dangerous and is leading to long term disability. The LC services in Wales are rehabilitation clinics, which should only be offered once medical assessment, diagnosis and treatment has occurred.".* • *"Feels as though purely management of symptoms"*	0	18	5

• *“[…] need medical intervention and diagnosis before we have rehab.”* • *“Lack of biomedical assessment. Too much emphasis on rehabilitation without finding out root causes of problems.”* • *“Investigations are needed into the cause of symptoms such as heart issues and neurological problems.”* • *“Allow for imaging/tests to be performed and referrals to specialities”* • *“Regular testing of vital organs to ascertain any long-term damage from COVID”* • *“Access to medical professional who can do/order tests that Long COVID MDT team cannot.”* • *“I’d like to see more testing for micro clots, brain changes and novel ways to see what is contributing to the severe malfunctioning of our homeostatic balance caused by the disease.“* • *“I think attending a clinic and having further medical tests, other than routine blood tests, would have been helpful to see if there was something amiss, e.g. scan or special chest/lung tests other than regular X-rays that often fail to reveal any issues.”* • *“Would be great if the staff in the Long COVID team had more governance in pushing for tests.”* • *“I feel that the Long COVID care in this area is very disjointed. I think that having a Long COVID Medical Specialist(s) within the team who would take patients concerns seriously, do tests, think outside the box using up to date research knowledge and then relating that to each individual treatment plan would be invaluable”* • *“I would have liked referrals regarding my brain issues and heart and lung issues which would have made me feel less anxious about my physical condition and not just coping with the situation I am in. Though that is helpful that is where I feel the service would be improved, by working more closely with doctors who can help diagnose any physical conditions”*			
Responders prefer face-to-face support • *“The course was online due to COVID-19 restrictions; this restricted interaction with others and therefore felt stilted at times”* • *“No face to face assessment once lockdowns had eased.”* • *“I […] think it is time for face to face appointments so that patients can be properly assessed.”*	0	7	8
Referral/access to the Long COVID service is too slow • *“Months wasted on referral waiting lists.”* • *“Being bounced around which after 1.5 years is frustrating. And exhausting”* • *“If you need referring to a specialist you have another ??months/years to wait for answers/diagnosis/treatment”*	1	6	7
Responders needed to find support independently • *“My problems now have been investigated (privately) and diagnosed as MS [Multiple Sclerosis]. Triggered by COVID. If the service included and neuro staff I may have had this picked up earlier and had help”* • *“It frustrates me because I’ve been on a waiting list to see a respiratory specialist for months and even though the team are pushing my doctors to fast track the tests, nothing seems to work. This has led to me seeking private care… which just shouldn’t be the case. This isn’t so much a problem with the Long COVID team but more of an NHS -wide issue… it just doesn’t seem right.”*	0	4	1

More/longer appointments needed • *"Course needed to be longer, not everything could be fitted in […] I have followed up with an online physiotherapist session; again, this is great but I feel we all need a more than 4/5 online sessions. Long COVID is so debilitating and life changing that I feel I need much more support than a one-off course."* • *"More frequent appointments - monthly not every 10 weeks."* • *"Wish some session could go over 1 hours"* • *"Think I needed more time with psychologist as 2 phone calls cannot get the overall picture as there are ups and downs with stress anxiety etc."*	0	2	2
Responders need more support with their job employers • *"More education to employers on a National scale."* • *"The team should be in contact with your place of work, liaising with the workplace."*	0	1	2

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 (Negative feedback – not specific for the Long COVID service)	Existing service users N = 6	Follow-up N = 71	Discharge N = 97
GP staff not prepared enough on Long COVID, not aware of Long COVID services and/or not supportive • *"GPs not knowing about programme"* • *"Often told to speak to GP about something but not able to actually access an appointment with GP. When GP appointment is finally accessed, GP refuses to act on MDT's suggestions."* • *"[…] They didn't dismiss the symptoms by telling me it was anxiety, which has on occasion been my experience with GP practice"* • *"Very poor service from GP - have had to advocate for myself with GP causing a lot of stress, and as a result will be changing GPs"* • *"Currently, accessing a GP is difficult enough, but when you eventually get a telephone appointment you're either told you have Long COVID and there's nothing can be done, or if you're very lucky the GP will run some tests. If those tests are 'normal' then the GP writes you off as if there is nothing wrong with you."* • *"Continuity with GP is non-existent and I haven't felt that they can be bothered."*	0	7	3
Responders felt scared and overwhelmed about their conditions, uncertain about their future • *"It's difficult dealing with something where there are not many answers"* • *"Avoid using the terms 'we just don't know' or 'there's not enough known' as this renders the patient feeling even more desperate and with a sense of hopelessness."* • *"It's still extremely frustrating that I'm making next to no progress"*	0	3	3

Table 16. Negative service user experience feedback (not 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)	Existing service users N = 6	Follow-up N = 71	Discharge N = 97
Provide more links to current research on Long COVID • *"Keep people informed of research and opportunities to help"* • *"There is now a wealth of research on possible helpful treatments for Long COVID but patients are not getting access to this."* • *"If the service could work alongside research projects I think that would be of benefit to all and allow research in the more unusual areas to be undertaken, these measures may be non-pharmaceutical and in the long term save money."* • *"Once the recent and future research is widely published/available to practitioners it would be good to see potential treatments explored and offered, as opposed to coping strategies that at present are the only options."*	0	3	1
Other suggestions • *"Teams sessions or group sessions would have been useful"* • *"Email summary for calls, action plans via emails"* • *"More information – electronic".* • *"Appointment emails would be better if they included date and time in email header. Particularly relevant for Long COVID brain fog patients".* • *"Provide hard copy of pacing guides"* • *"Allowing & encouraging GPs & consultants to prescribe medications off- label will really help us."* • *"[…] prescribing and supervision of existing pharmaceutical treatments […] could really help."* • *"I am part of a worldwide Facebook Long COVID Group which is monitored by clinicians. It's ok but could be a really valuable tool and resource if people shared tools and advice. I would really like to be part of a local self-help group which had a health and well-being focus."* • *"A neuropsychological assessment to inform whether someone is safe to return to work & drive a car, should be made available to those who need it"*	1	13	10

Table 17. 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: 89.9% of the 'Follow-up' group and 88.3% of both 'Existing service users' and 'Discharge' groups.

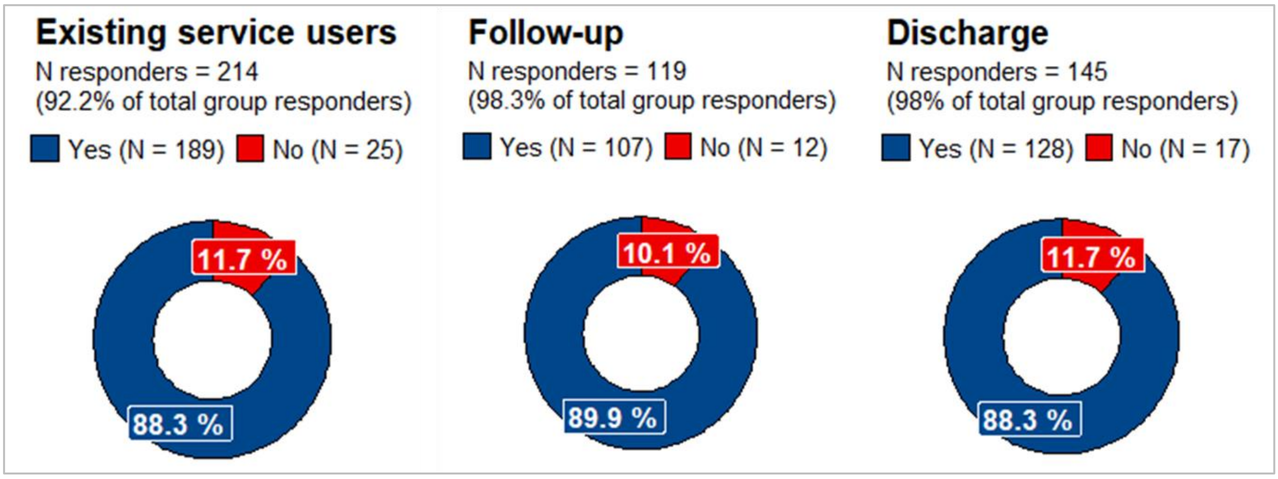


Figure 17. **Donut charts for [Q21]: "*Would you recommend this service?"*** (% of responses by LHB - AB UHB: 5%; BC UHB: 1.5%; CAV UHB: 20.7%; CTM UHB: 43.2%; HD UHB: 12.4%; PT HB: 4.6%; SB UHB: 12.7%).

3.8 Analysis of additional responses

A total of 198 responses were excluded from the main analysis following the criteria described in Section 2.1.5. These extra responses, from responders who did not access the Long COVID service, were analysed separately below.

Starting with their demographics (Table 18, Figure 18 and Figure 19), the majority of additional responders were females (76.3%,), the most frequent age range was 41-50 (35.9%), most responders were of '*Any White background*' ethnicity (97.4%) and the most frequent employment status was '*Full-time employed/self-employed*' (43.4%).

		Additional responders
	Total sample size	**198 (100%)**
Gender	**Female**	151 (76.3%)
	Male	46 (23.2%)
	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	29 (14.6%)
	41 - 50	71 (35.9%)
	51 - 60	70 (35.4%)
	61 - 70	22 (11.1%)
	71 - 80	1 (0.5%)
	81 - 90	0 (0%)
	91 and over	0 (0%)
Language used to respond	**English**	198 (100%)
	Welsh	0 (0%)

Table 18.Demographics of additional responders.

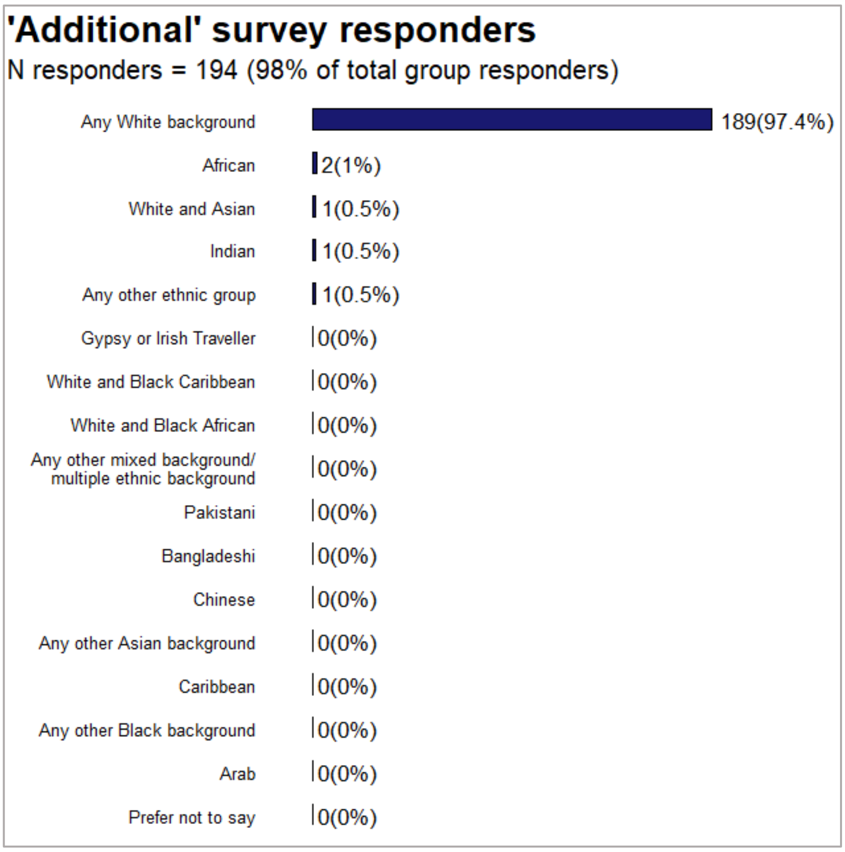


Figure 18. Bar plots for: [Q3] **"*Please tell us your ethnicity*".**

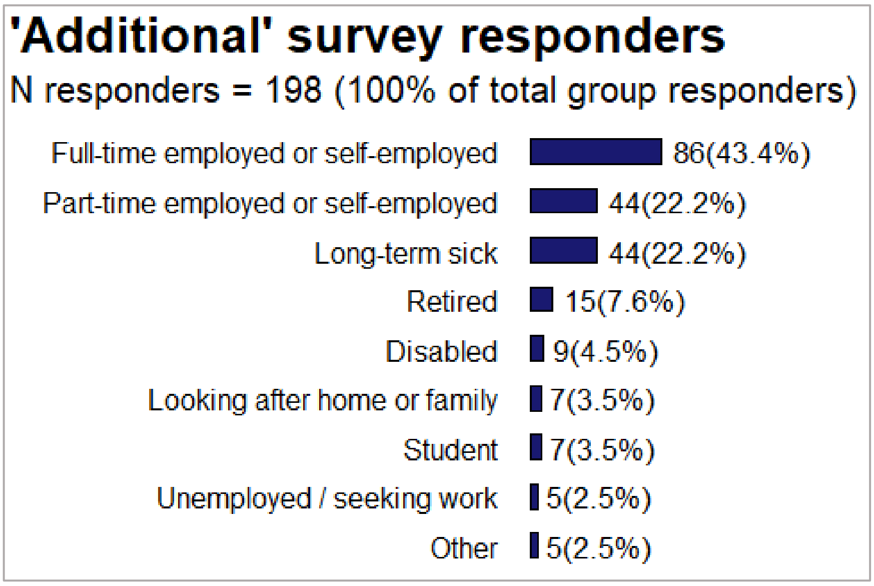


Figure 19. Bar plots for: [Q4] "*Which of these definitions describe your employment status?*" Multiple responses per responder were allowed for this question (i.e., for each bar, 100% would represent that all responders chose that option).

The COVID-19 related symptoms experienced by the majority of additional responders were: '*Fatigue*' (89.9%), '*Brain fog*' (85.9%), '*Shortness of breath*' (77.8%), '*Joint pain*' (68.7%), '*Headache*' (61.1%), '*Insomnia*' (60.6%), '*Dizziness*' (57.1%), '*Chest pain/tightness*' (56.1%), '*Heart palpitations*' (55.1%) and '*Depression and anxiety*' (51.5%).

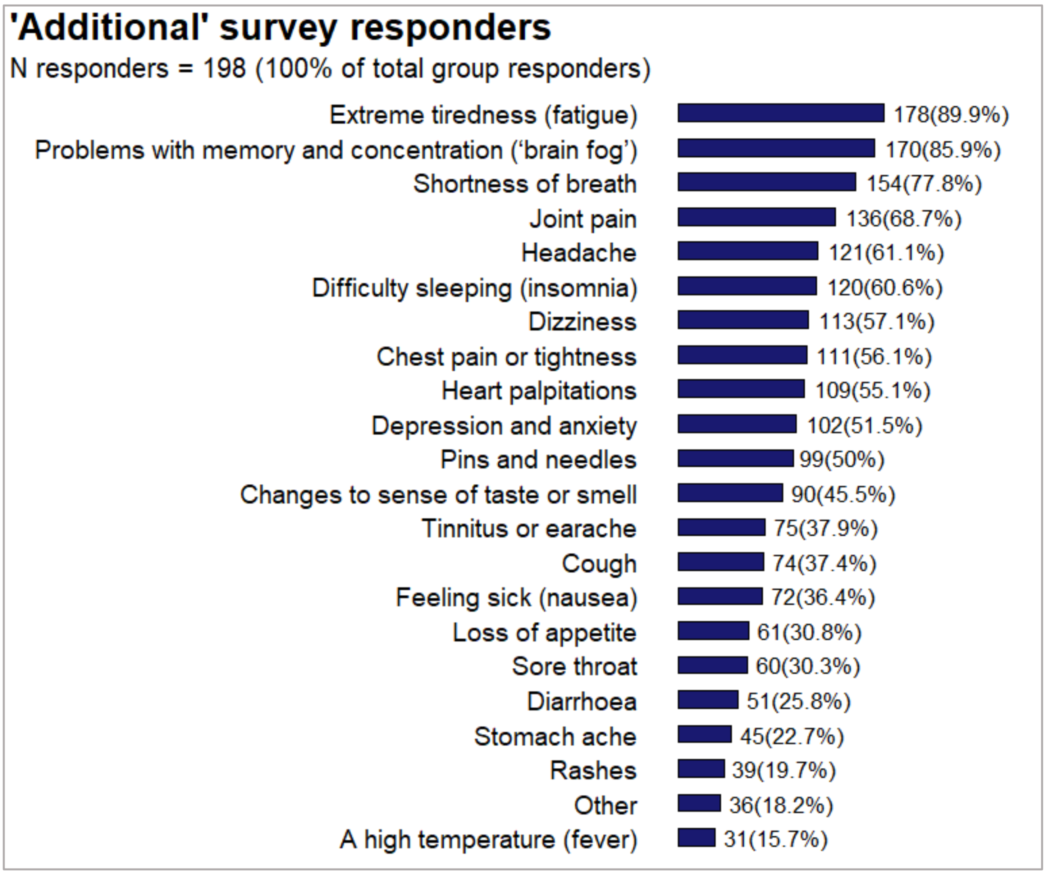


Figure 20. **Bar plots for [Q6]: *"Please tell us about any symptoms you have experienced today due to COVID-19"*.** Multiple responses per participant were allowed for this question (i.e., for each bar, 100% would represent that all responders within the group chose that option).

Similar to what was reported by Long COVID service users, the 'additional' responders most frequently mentioned the following 'other' symptoms: '*Pain*', '*Mobility issues*', '*Vision and eye issues*' and problems with '*Voice, mouth, throat and/or swallowing*' (Table 19).

OTHER SYMPTOMS	'Additional' responders N = 35 (17.7%)
Pain (e.g muscle pain/stiffness, general or localised pain in the body)	9 (25.7%)
Mobility issues (including leg issues, balance issues)	7 (20%)
Vision and eye issues	5 (14.3%)
Voice, mouth, throat and swallow issues	4 (11.4%)
Post-exertional malaise	4 (11.4%)
Hair loss	3 (8.6%)
Cardiovascular issues (e.g. tachycardia)	2 (5.7%)
Dysautonomia issues/Postural Orthostatic Tachycardia Syndrome (POTS)/ Orthostatic Intolerance	2 (5.7%)
Numbness of body (e.g. feet, face)	2 (5.7%)
Excessive sweating/feeling hot and/or inability to regulate body temperature	2 (5.7%)
Allergy, MCAS (Mast Cell Activation Syndrome)	1 (2.9%)
Constant muscle fasciculations	1 (2.9%)
Issues with limb extremities (cold, sore, itching, swelling)	1 (2.9%)
Flatulence	1 (2.9%)
Gastrointestinal issues	1 (2.9%)
Swollen glands	1 (2.9%)
Hearing loss	1 (2.9%)
Hypersensitivity (e.g. to light, sound, pain or skin hypersensitivity)	1 (2.9%)
Hypertension	1 (2.9%)
Involuntary tremor	1 (2.9%)
Mood issues (e.g. extreme mood swings, low mood)	1 (2.9%)
Nose and/or sinus issues (e.g. nose bleed, nasal inflammation, sinus congestion)	1 (2.9%)
Vivid dreams, nightmares, waking up sharp with anxiety	1 (2.9%)
Under-active thyroid	1 (2.9%)
Transient ischemic attack	1 (2.9%)

Table 19. 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

Finally, 12 'additional' responders (6% of total 'additional' responders) provided feedback via free text (these responses were collected between the 1st of January 2022 to the 31st of March 2022; see Appendix 7 for the thematic analysis of previous 'additional' responses). The main theme emerging was a feeling of having been forgotten or not supported enough to get help for Long COVID:

- *"I have had no support, my GP believed me but can't offer any help. I have seen several hospital doctors, only 1 doctor I had to pay private to see believed my symptoms but could not offer anything that has helped."*
- *"I didn't receive my phone call and only realise I was dropped off the List when I went for a follow up appointment with my consultant and the reason I give was that I was fine and didn't need any help which I never had that conversation. Disgraceful."*
- *"Cannot get referred to long COVID clinic".*

4 Social Return of Investment (SROI) analysis

Both C&V UHB's and CTM UHB's Long COVID Rehabilitation Services have been running for slightly over one year, and have multi-disciplinary teams including physiotherapists, occupational, speech and language therapists. There is also provision from psychologists, GPs and dietitians in some teams. Both services perform one-to-one assessments and interventions. C&V UHB have used group interventions from the start and CTM UHB have carried out one face to face group, following user feedback. Additional group provision has been made available via the Welsh National Opera programme at both sites.

Service users have been the main stakeholders to provide feedback, and the key outcomes reported by questionnaire responders and interview participants were the feeling of being listened to, understood and believed, and, where groups were available, meeting (virtually) other people who were going through the same experiences. For many people the impact of these was a turning point in how they felt, although this may depend on the support they had been able to access from other routes. In addition, people mentioned the understanding that they had to pace themselves and not try to "push through", and how information such as an occupational therapist's plan for return to work could help them cope better. This information helped people feel they had a means to explain to colleagues or family how gradual progress might be, and the impact of Long COVID. In contrast, changes in health was not mentioned as often in questionnaires or interviews, although for some individuals there were specific interventions that were very important in changing their health outcomes.

We have also gathered limited data from GPs, secondary care providers and one employer as part of the wider stakeholder impact mapping. Feedback from GPs was mixed, with some GPs feeling that the service had not had an impact directly on their practices, or not being aware of the service. However, several GPs felt that the service had helped to reduce repeat visits, and another appreciated having a multi-disciplinary team for referrals. Initial conversations with an employer suggest that although Long COVID has had an impact, they have not identified a benefit directly from the service. This may be related to the very long and gradual recovery process. Service users reported that phased return to work plans, created with the Occupational Therapists, were very helpful in understanding their gradual nature and in communicating this effectively with employers. We were unable to gather evidence from families of people with Long COVID, however there was some very limited information from service users that they had been able to improve communication and planning in ways that helped their relationships with family.

The SROI calculation found that both interventions have a social value ratio of greater than 5, meaning that for every £1 put in, there is a much greater return in value to the included stakeholders, even with the relatively conservative assumptions being made.

5 Local Health Boards demand data

Table 20 shows the demand for accessing the Long COVID service in the various LHBs (we asked whether they could have provided the numbers from when they started to receive funds from the Adferiad programme). 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	251	678	424	661	254	95	372
Number of individuals who have got access to and used the Long COVID service	124	200	291	425	113	61	241
Number of Long COVID service users who have been referred to secondary care as outpatients	21	8	44	45	0	0	31

Table 20. Demand for accessing the Long COVID service. *numbers refer only to core services and do not include AB UHB courses delivered by a third-party.

Table 21 shows when the information was collected for Table 20.

Local Health Board	From	To
AB UHB	01/05/2021	31/03/2022
BC UHB	02/12/2021	31/03/2022
C&V UHB	01/09/2021	31/03/2022
CTM UHB	01/07/2021	31/03/2022
HD UHB	18/10/2021	31/03/2022
PT HB	01/07/2021	31/03/2022
SB UHB	01/08/2021	31/03/2022

Table 21. Collection period of service demand data from LHBs.

6 References

Lopez-Leon, S., Wegman-Ostrosky, T., Perelman, C., Sepulveda, R., Rebolledo, P. A., Cuapio, A., & Villapol, S. (2021). More than 50 long-term effects of COVID-19: a systematic review and meta-analysis. *Scientific Reports*, *11*(1), 1–12. https://doi.org/10.1038/s41598-021-95565-8

NICE. (2021). *Guideline NG188 | COVID-19 rapid guideline: managing the long-term effects of COVID-19*. https://www.nice.org.uk/guidance/ng188/chapter/Recommendations

NIHR. (2021). *Living with COVID-19 - Second Review (March 2021)*. https://evidence.nihr.ac.uk/themedreview/living-with-covid19-second-review/

ONS. (2021a). *Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK: 1 April 2021*. https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/1april2021

ONS. (2021b). *Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK: 2 December 2021*. Office for National Statistics. https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/2december2021

Social Value UK. (2012). *Guidance and Standards*. https://socialvalueuk.org/resources/sroi-guide/

Sudre, C. H., Murray, B., Varsavsky, T., Graham, M. S., Penfold, R. S., Bowyer, R. C., Pujol, J. C., Klaser, K., Antonelli, M., Canas, L. S., Molteni, E., Modat, M., Jorge Cardoso, M., May, A., Ganesh, S., Davies, R., Nguyen, L. H., Drew, D. A., Astley, C. M., … Steves, C. J. (2021). Attributes and predictors of long COVID. *Nature Medicine*, *27*(4), 626–631. https://doi.org/10.1038/s41591-021-01292-y

Van Hout, B., Janssen, M. F., Feng, Y. S., Kohlmann, T., Busschbach, J., Golicki, D., Lloyd, A., Scalone, L., Kind, P., & Pickard, A. S. (2012). Interim scoring for the EQ-5D-5L: Mapping the EQ-5D-5L to EQ-5D-3L value sets. *Value in Health*, *15*(5), 708–715. https://doi.org/10.1016/j.jval.2012.02.008

Welsh Government. (2021). *Technical Advisory Group: Long-COVID*. https://gov.wales/technical-advisory-group-long-covid

Whitaker, M., Elliott, J., Chadeau-Hyam, M., Riley, S., Darzi, A., Cooke, G., Ward, H., & Elliott, P. (2021). Persistent symptoms following SARS-CoV-2 infection in a random community sample of 508,707 people. *MedRxiv*, 2021.06.28.21259452. https://www.medrxiv.org/content/10.1101/2021.06.28.21259452v1

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

Q4a. If other, please specify

____

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

____

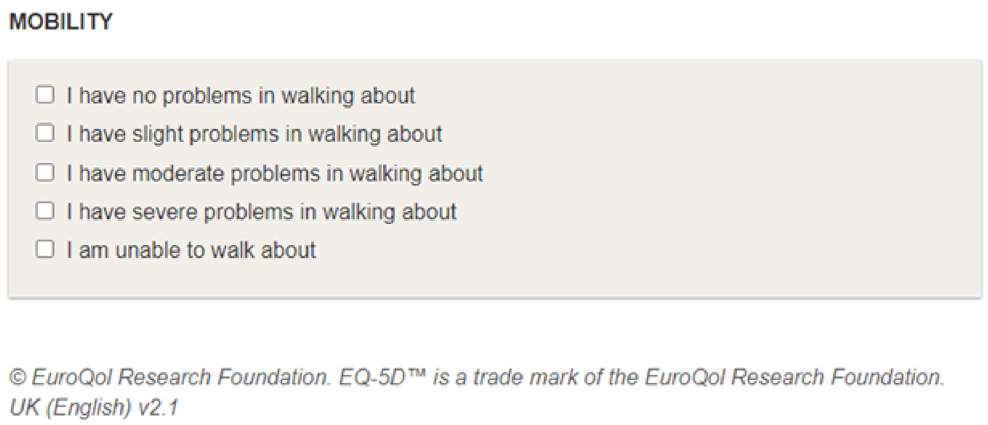
Q8. If you have had rehabilitation related to your COVID-19, please tell us how many sessions/appointments you have had.

____

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

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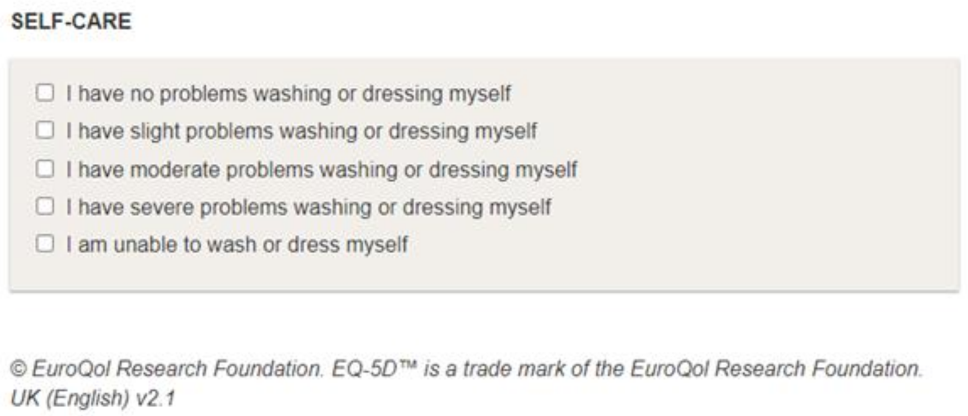
Q10. Please select the ONE box that best describes your health TODAY: SELF-CARE



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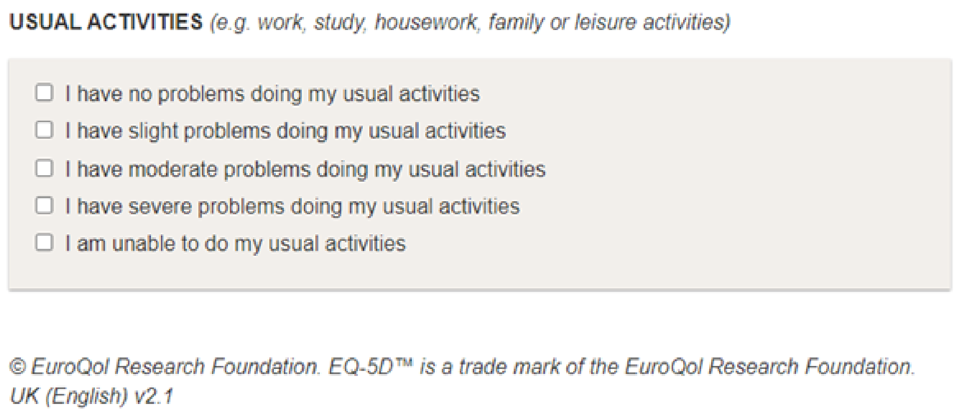
Q11. Please select the ONE box that best describes your health TODAY: USUAL ACTIVITIES



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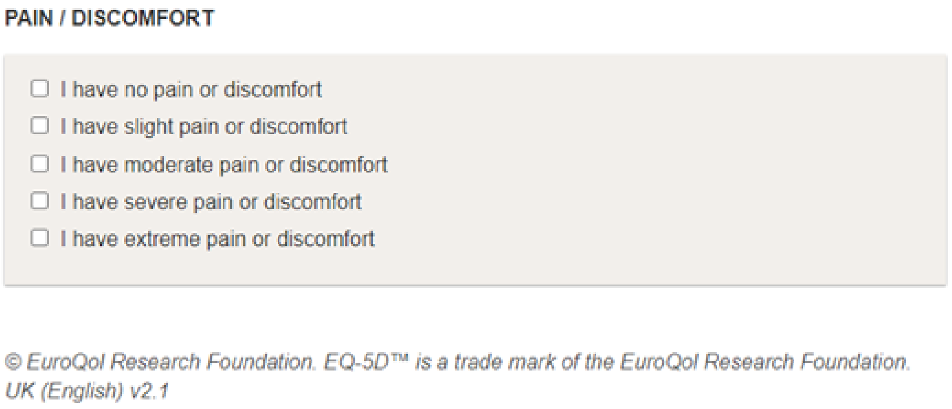
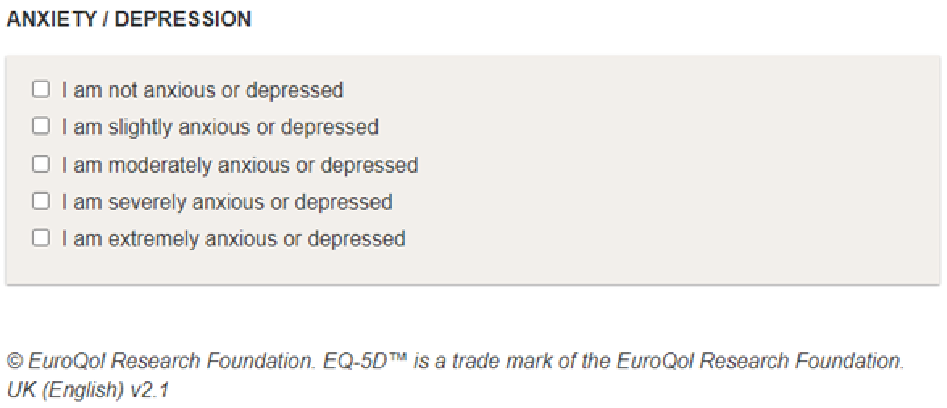
Q12. Please select the ONE box that best describes your health TODAY: PAIN / DISCOMFORT



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

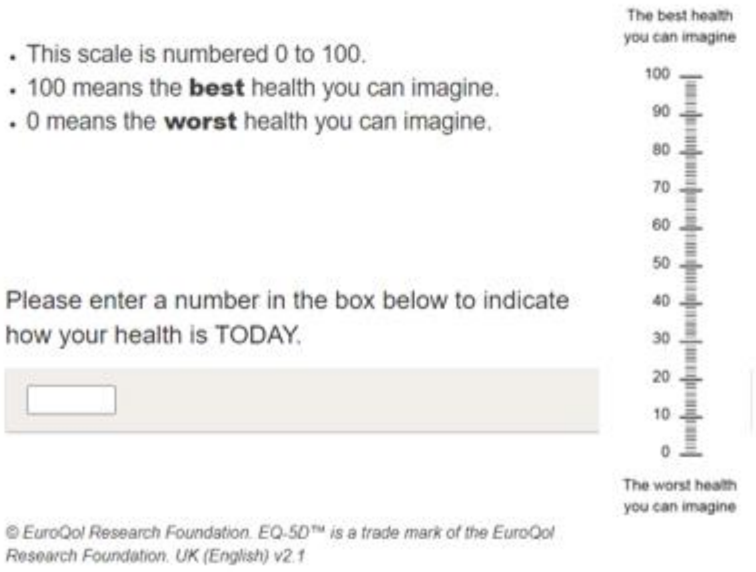
Q13. Please select the ONE box that best describes your health TODAY: ANXIETY / DEPRESSION



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

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.

☐

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’ **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’

Appendix 3: Positive feedback themes extracted from Q19 and Q20 free text responses from main analysis in January 2022 report

Responses collected between 1st of September 2021 and 31st of December 2021. For each service user group, the number of responders (N) is reported in the column header.

Themes (Positive feedback)	Existing service users N = 177	Follow-up N = 25	Discharge N = 37
Responders felt put at ease, listened to and acknowledged by the Long COVID team • *"Getting information and somebody listening and understanding, believing in you. Being referred to the hub gave my condition legitimacy - taken seriously"* • *"The Long COVID service, despite limited funds and incomplete knowledge, has been a start to acknowledge those post-viral struggles people get"* • *"It's kept me going knowing that I can talk to you. Address concerns, listen to concerns and give advice. Nice to have someone to talk to. At the end of the phone if I need you. I know I have back up at the end of the phone"* • *"The fact you've contacted me when you said that you would, answered all my questions, spent a long time on the phone to me going through lots of details"* • *"Some people don't believe Long COVID exists and roll their eyes at me. You have listened"* • *"I feel supported by the hub, it makes the situation bearable, before I was in a state of despair"* • *"Staff in Long COVID hub are very kind and take time to let me explain"* • *"Staff were always supportive & listened & offered help/advice where they could"* • *"Nice to talk to someone who wants to help"* • *"The Long COVID rehab team have been very supportive and made me feel like I'm not so isolated"* • *"Good to talk to someone and be believed about experience"* • *"The Long COVID service can be contacted immediately gives comfort feel less alone knowing a service that's understands me"* • *"Glad to have someone to talk to that understands and a safe place to talk. Really appreciate it"* • *"Personable and friendly, approachable, easy to open up to"* • *"All 3 professionals are kind, compassionate and validating that I've spoken to really helpful"* • *"I felt as though I was listened to and believed which was a huge positive for me"* • *"We have never felt alone during this difficult time"*	50	13	13
Responders found the Long COVID service staff knowledgeable and the advice/treatment they provided helpful • *"The presenters of the course were excellent and took their time to explain and listen"*	32	7	11

• *“The* [Long COVID service] *staff really care and are learning constantly”* • *“They* [Long COVID rehab team] *have lots of knowledge”* • *“New techniques and advice so I can support myself”* • *“Feel more confident with information and contact”* • *“Helped me out, that's all I needed”* • *“Sent out useful information and explained things to me”* • “[I was] *given achievable strategies.* [You were] *telling me things I can understand”* • *“All aspects of the course were very helpful”* • *“It’s the guidance you've given […]. It’s really helpful and relieved my symptoms“* • *“Helped relieve anxiety/worry. Excellent and supportive care and correct investigations”* • *“Everyone I've spoken to knowledgeable”* • *“I thought the course was very good”* • *“I found you to be helpful. Materials very helpful and useful. You're top class and helped me tremendously”* • *“All the advice, I have followed and makes so much sense and made such a huge difference. It’s been great”* • *“Long COVID clinic […] supportive and diagnosed my nerve damage”* • *“It’s been lengthy and thorough, covered every angle. Has received some helpful advice”* • *“All the tips have been really helpful and I have felt better from following them”* • *“Given me the tools. If it wasn't for you, I've come so far. I'm so grateful”*			
Responders mentioned specific components of the Long COVID service that improved their recovery • *“Explanation of breathing, videos how to breath properly, gives you back control”* • *“Breathing exercises helped 100%, feels better in 2 weeks”* • *“Pack that was sent was helpful and dry mouth samples sent by speech”* • *“I think the Physio I’ve spoken to so far is fantastically helpful and doesn’t dismiss any information I offer on my condition or treatment”* • *“The ‘Managing Fatigue’ course is very good”* • *“Useful speaking to the speech therapist, useful to understand and know what is going on”* • *“I have been supported emotionally as well as rehab for my mobility”* • *“The meditation helps to take me out of my feelings”* • *“One individual occupational therapist who is helping me with my recovery has been excellent. She has stressed the importance of rest and provided excellent continuous support and individualised literature to aid my progress with multiple symptoms”* • *“When I first attended the pulmonary course I was very short of breath and coughing a lot. I learnt new skills such as breathing techniques to help me cope”*	14	7	4

- *“Education on pacing & breathing techniques. Gradual return to exercise (boom &bust) […] Acceptance of condition and anxiety management. Eating right food for exercise. Advice from NERS* [National Exercise Referral Scheme] *team. Appropriate referral re long term affects”* - *“OT* [Occupational Therapy] *is amazing! Information and holistic OT support amazing.”*			
Responders valued the group sessions, which allowed them to get mutual support, sharing and recognition from the interaction with other service users - *“Good to speak to others who feel the same”* - *“Online sessions good with understanding people who shared their own experiences”* - *“Opportunity to talk to others in similar situations and to not feel alone”* - *“If we can help each other and have each other for support it makes such a big difference”* - *“It’s beneficial to share your experiences of fatigue with other people on the course that also experience fatigue, and listening to their experiences too”*	21	0	2
Responders felt the Long COVID service was personalised around their needs - “*The recovery program is catered for my needs*” - “*It has been very collaborative, not prescribed, very individualized*” - “*He* [staff from multidisciplinary team] *tailored his advice to my situation and answered all my questions with thought*”	3	0	0

Appendix 4: Negative feedback themes (Long COVID service-specific) extracted from Q19 and Q20 free text responses from main analysis in January 2022 report

Responses collected between 1st of September 2021 and 31st of December 2021. For each service user group, the number of responders (N) is reported in the column header.

Themes (Negative feedback – specific for the Long COVID service)	Existing service users N = 177	Follow-up N = 25	Discharge N = 37
Referral/access to the Long COVID service is too slow • *“Took x4 months to be referred on from the GP referral for an appointment at service”* • *“Time it took to speak from the referral to the appointment (the GP told me that I was referred in May but I didn't receive contact until July”* • *“Referred Jan/Feb and seen in August”* • *“It would have been nice to speak to someone from the hub earlier - I had to wait six months since being home from hospital […]”* • *“Too long between discharge from hospital and first contact with Long COVID service”* • *“Access to an initial triage needs to be immediate to give advice re ability to work and the pacing approach. […]. I accept that waiting lists exist but something needs to be given for you to work with whilst awaiting therapy.*	23	2	5
Those with Long COVID needed to find support independently • *“I was in a position to pay for that physio advice so was able to help manage the condition from day 1 whilst awaiting NHS support. This gave me 3 months 'headstart' rather than another 3 months of making my condition worse”* • *“I’ve been paying for breathing lessons myself, learnt about balanced diet myself”* • *“No support for chronic fatigue. I have found out about pacing on Long COVID Wales website”*	9	0	1
The advice/treatment offered is too generic and not enough tailored around individual needs • *“I have an underlying chronic condition and disability which is multi-systemic and have developed more autoimmune issues. The service currently can’t deal with separating out these issues from Long COVID and I suspect they make each other worse”* • *“No knowledge or recognition that Long COVID can be like ME/CFS* [Myalgic Encephalomyelitis/Chronic Fatigue Syndrome] *with orthostatic intolerance and that exercise is contraindicated for these conditions. I would recommend this for people to be heard and for their Long COVID symptoms to be recorded even if the exercise is unsuitable for them. It is slightly better than nothing but not appropriate for all”* • *“Staff knowledgeable and teaching excellent but too much emphasis on exercise which is not appropriate for many with Long COVID”*	11	2	2

• *"Maybe a one on one session for individual needs may have enhanced experience"*			
Uncertain support after Long COVID service discharge • *"Please make sure those suffering from Long COVID are not discharged and left to suffer as I don't want anyone to live with a life in chaos in addition to the value judgements that will invariably follow i.e. like the ME* [Myalgic encephalomyelitis]*/chronic fatigue patients have had for years"* • *"The experience was very positive but once done there's a bit of a feeling of being forgotten about because what else can anyone do?"* • *"What happens going forward after being discharged from rehabilitation?"*	3	0	1
Long COVID service was not helpful • *"No caused more anxiety and stress"* • *"The Long COVID service is not fit for purpose. Poor practitioners with no knowledge or care for Long COVID sufferers"* • *"No improvements with clinic"*	3	0	1

Appendix 5: Negative feedback themes (not specific for Long COVID service) extracted from Q19 and Q20 free text responses from main analysis in January 2022 report

Responses collected between 1st of September 2021 and 31st of December 2021. For each service user group, the number of responders (N) is reported in the column header.

Themes (Negative feedback – not specific for the Long COVID service)	Existing service users N = 177	Follow-up N = 25	Discharge N = 37
GP staff not educated enough on Long COVID, not aware of the Long COVID service and/or not supportive • *"More awareness at GP practice"* • *"Speaking with certain GP I didn't always feel listened to"* • *"Educate GP's more about Long COVID and how they can help"* • *"Conflicting information given by GP'S a standardised approach required"* • *"We have been told to go to our GPs to discuss our symptoms, but they haven't got enough time or expertise to deal with the complexities of Long COVID & there is no continuity of care as you speak to a different person each time"*	26	2	4
Responders feel forgotten • *"Since triage I have found out that there are now more options for treatment of my symptoms but that I was triaged at the wrong time and therefore missed out. It would be good to stay in the system and be returned to as new treatments come into existence"* • *"For the first 12 months of post COVID syndrome the lack of support was very hard"* • *"I was ill a lot so couldn't do a few of the sessions so missed out a lot so didn't get to fully benefit"* • *"I was lost in system and that was bad - had to fight for input"* • *"At first after hospital it felt 'now what' chucked out and left to get on with it"*	15	2	5
Responders feel invisible and that their Long COVID issues are not believed • *"Lots of the symptoms aren't visible and so it can be difficult to get support from family and work"* • *"Left alone to deal with effects of COVID there were interminable long periods when you felt invisible"* • *"As my symptoms weren't respiratory I felt that I was almost put into the reject pile because there wasn't a clear recovery path yet the symptoms I have had since COVID have been life changing"*	5	0	0
Responders need more support in dealing with employers • *"More support and understanding and an improved knowledge of the condition by managers with an emphasis on flexibility as it is impossible to predict when I'm going to have a good day and a bad day. The condition should be considered a disability to ensure protection within the working environment and to ensure financial support for loss of income when I am able to return to work on reduced hours initially"*	7	0	1

• *“More employment support, particularly for healthcare staff due to pressure for us to go back into work”* • *“A better understanding of COVID should be given to employers”* • “[Tell me] *what financial support I could have due to being off work for a substantial length of time”* • *“Help get longer time off as we can't live like this trying to work and survive”*			
Responders feel scared and overwhelmed about their conditions, uncertain about their future • *“Without wanting to be dramatic Long COVID is life changing for me”* • *“My experience has been life changing, I wish we could erase he last 18 months of COVID so I can get back to normal, whatever normal will be”* • *“I’m grateful for the course but the fact still remains that I’m still suffering from post COVID syndrome. And it’s a bit scary not knowing if/when I’ll feel well again”* • *“I’ve never felt so ill and alone, it’s been over a year for me”*	13	0	0

Appendix 6: Suggestion for improvement themes extracted from Q19 and Q20 free text responses from main analysis in January 2022 report

Responses collected between 1st of September 2021 and 31st of December 2021. For each service user group, the number of responders (N) is reported in the column header.

Themes (Suggestions for improvement)	Existing service users N = 177	Follow-up N = 25	Discharge N = 37
Responders prefer face-to-face support • *"The staff were lovely and great to be face to face"* • *"Staff were kind and friendly and being seen face to face was important"* • *"Face to face contact would be better but appreciate it's not possible at the moment"* • *"Video call would be better"* • *"Due to the nature of the pandemic, virtual sessions were needed. This had advantages of being accessible but did make discussion difficult at times"*	12	6	6
Increase the frequency of appointments • *"Increase frequency of appointments, 15-minute appointment every 10 weeks is not sufficient to help me recover"* • *"Only one choice of days times which coincided with work. Difficult to engage"* • *"Appointments are far apart"* • *"Make appointments more regular, every 10 weeks is not enough"*	5	0	0
Responders would like group therapy with others suffering with Long COVID symptoms • *"I would like to go to a group and meet other people through the same thing"* • *"Only advice and information from hub, I would like patient groups"*	2	2	1
More suggestions for improvement **Some responders suggested to keep those suffering from Long COVID informed and monitored in the months ahead, since the disease is still not well understood:** • *"To log all illness ongoing for maybe a year or two to find out if there is a pattern emerging"* • *"I would like to be informed of changes to recovery as more research and evidence is discovered"* • *"Possibly a review after another period of time - say 6 months- to see if things have changed or understanding of COVID has changed"* **Some responders recommended making referral easier** • *"It would be better if they could make onwards referrals instead of having to go back through to the GP"* • *"More continuity between services and easier referrals"*	14	2	4

Some responders would prefer more electronic communication: • *"When somebody was off sick - I would have appreciated being told before the appointment time. Then when the appointment time was rearranged, I got it wrong due to my memory - a text reminder would have been useful"* • *"Allowing people (especially with disabilities such as autism) to communicate via email to make it more accessible"* • *"Electronic appointments (text/email) would be better"* • *"communication- sending of information electronically"* **Some responders reported services for people with Long COVID are not known well enough:** • *"Contact details were poor, needed to chase up. Switchboard didn't recognise the service"* • *"Feels more publicity is needed"* • *"Some people still not aware of COVID team"* **Other suggestions:** • *"Explain things in 'layman' terms"* • *"Admin could improve, letters have been received after appointment"* • *"More support on managing fatigue and cognitive issues"* • *"More consultant-led Long COVID clinics in all HB's covering all specialty's cardiac, respiratory and neurological"*			

Appendix 7: Additional responders' themes extracted from Q19 and Q20 free text responses from additional analysis in January 2022 report

Responses collected between 1st of September 2021 and 31st of December 2021, from responders who did not access the Long COVID service. The number of responders (N) is reported in the column header.

Themes	'Additional' responders N = 132
Responders feel forgotten • *"No help for Long COVID"* • *"I have not been contacted by anyone concerning this because I caught it Jan 2020"* • *"I had mild COVID April 2020 I wasn't followed up to see how I was afterwards"* • *"Haven't had any care. Not seen anyone"* • *"I have felt totally unsupported during my very scary experience of thinking my end was near on several occasions with no medical support"* • *"Actually contact people instead of just a survey"* • *"Have a point of call. There is no-one to speak to individually. I just feel like I'm left to cope on my own"* • *"More information needed as there is none"* • *"I'm still waiting for referrals and feel I'm forgotten about"*	50
GP staff not prepared in dealing with Long COVID, not aware of the Long COVID service and/or not supportive • *"The GP has no idea when I might hear back neither can they give any indication of the waiting time/list"* • *"GPs are not specialist in treating any of the illnesses brought on as a result of COVID, whether it is blood clots, MCAS* [Mast Cell Activation Syndrome] *or dysautonomia. These are serious conditions requiring specialist help"* • *"Don't feel listened to by GP, don't feel as though GPs are educated enough to deal with this […] difficulty getting GP to take bloods/run tests despite new symptoms"* • *"I have given up even trying to ring the GP as the effort is too much and so frustrating"* • *"Educate doctors more. I have been I'll for 18 months. Lost my job. In arrears for rent and council tax. Still my doctor tells me to rest and take over the counter painkillers"* • *"Educate GP's (and staff) […] My GP had absolutely no idea what to do or what was available to help. I gave him the information I had researched"*	31

• *"Get GP's back to work seeing Long COVID patients! Also train them in symptoms and what referrals they can make. There needs to be a flow chart of procedures to follow for GP's so there is consistency from all Health Boards"*	
Referral/access to the Long COVID service is too slow • *"Regarding the Long COVID service, I was put forward to attend by my doctor and am still waiting, several months later. Therefore, I am unable to comment on my experience as I haven't seen anyone yet apart from my GP"* • *"I have been referred to the Long COVID clinic and should have been seen by a dietician for excessive weight loss but still haven't received an appointment"* • *"Still haven't been seen since over 4 months after Long COVID clinic referral. No-one has even been in contact. The lack of service is shameful"* • *"I've not received any treatment regarding Long COVID, still waiting for an appointment"* • *"I had COVID in feb/march 2020 and today I had a phone call offering me either a Long COVID clinic or a copd rehab course. It would have been so nice to get some help sooner"*	27
Responders do not know how to access Long COVID support or are not aware of any service • *"I have not been offered a Long COVID service. There are none in my area (Pembrokeshire). I have not been offered any treatment or support since contracting COVID in March 2020"* • *"What services?? Not aware of any in my area?"* • *"Why are there no Long COVID clinics in Wales?"* • *"I am not clear to what you are referring by "Long COVID service". AFAIK* [As Far As I Know] *Wales does not have a post- COVID service"* • *"There is no Long COVID rehab in ABHB area for those who were not hospitalised with COVID"*	20
Lack of resources/capacity • *"I think there need to be more access and help for people with Long COVID in Wales. We are not having much help"* • *"A series of dedicated multi-disciplinary centres throughout Cymru for the treatment and research of Long COVID sufferers is essential"*	5
Lack of Long COVID clinics in North Wales • *"Provide clinics in North Wales"*	4
Responders needed to find support independently • *"The only rehab support I have had is via Nuffield programme which I found out about through the Long COVID Wales group"*	17

• *“I got on the COVID programme in Nuffield, by finding it myself”* • *“I’ve had to go private as the waiting list for help is so long and appointments organised months in advance are cancelled”* • *“The Long COVID Wales support group on Facebook recommended the right doctor to see in Cardiff”* • *“The Long COVID Wales page on Facebook has been a TOTAL blessing! Don't know where I'd be without them !!!!!”*	
Responders feel that a “one-stop shop” COVID clinic is needed • *“One stop outreach service where we get referred to the right people for investigations”* • *“Have a one stop shop accessible to all”* • *“Central Long COVID clinics”* • *“Have a one stop hub Long COVID sufferers. Consultant led. Multi-faceted for all symptoms”*	8
Other suggestions for improvement • *“Have more info available online to help with Long COVID”* • *“Need multi-disciplinary treatment as Long COVID affects so many different things”* • *“COVID 19 rehab pack be useful for patients to start something as waiting list so long. Not everyone is on line to access or research COVID recovery whilst waiting”* • *“Provide clinics with diagnostic services, Long COVID can’t be rehabilitated away, believe me I’ve tried to my detriment”* • “[Offer] *ownership of rehabilitation plans”*	7