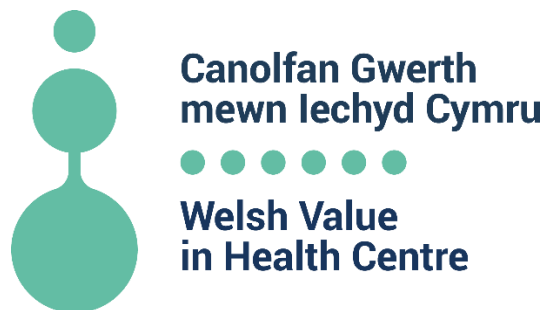


‘Adferiad’ (Recovery) Long COVID Service National Evaluation



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Summary

- This report contains the results of a cross-sectional survey administered between the 1st of September 2021 and the 31st of December 2021 to those accessing Long COVID services in Wales provided by the seven Local Health Boards and funded by the 'Adferiad' (Recovery) programme. 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 feedback on the experiences they had with the Long COVID service.
- Responses were collected from four service user groups: 'Existing service users' (223 responders), 'New referrals' to the service (295 responders), 'Follow-up' (32 responders) and 'Discharge' (39 responders). In all four groups: the majority were women, the most frequent age range was 51-60, most of the participants were of 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'.
- In all four service user groups, less than 27% had to be admitted to hospital due to COVID-19. The 'Follow-up' group spent a median of 36 days in hospital, the 'Discharge' group 20 days, the 'Existing service users' group 9 days, and the 'New referrals' group 4 days.
- The 'Follow-up' group had a median of 5 sessions with a general practitioner (GP) related to COVID-19, while the other groups had 4.
- The 'Follow-up' group had a median of 6 rehabilitation sessions due to COVID-19, the 'Discharge' group had 5, 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 the 'New referrals' group ($p = 0.016$; median EQ-5D-5L index = 0.67 and 0.54, respectively). A similar result was obtained using the EQ-VAS ($p < 0.001$; median EQ-VAS = 65 for 'Discharge' group and 50 for 'New referrals'). In addition, the 'Discharge' group also had a significantly higher EQ-VAS ($p = 0.005$) than the 'Existing service users' group (median EQ-VAS = 50).
- When asked about their experiences with the Long COVID service, the majority of responders 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 *'involved enough in deciding what support they received'* than any other answer option. More than 70% from all three groups rated their overall experience with the Long COVID service above average (i.e. >5), and more than 87% of all three groups would recommend the service. In general, the 'Follow-up' and 'Discharge' groups tended to rate the service higher than the 'Existing service user' group.



- Analysis of service user experience free text revealed some of the reasons why responders highly valued the Long COVID service they accessed: they felt listened, acknowledged, supported by knowledgeable and empathetic professionals who provided them with helpful advice and therapy and recognised their condition. The possibility for some of the responders to have access to group sessions where they met others suffering with Long COVID symptoms made them feel less lonely in their struggles and inspired a sense of mutual support.
- These aspects of feeling acknowledged and supported by the long COVID service and not feeling alone contrasted with a general background of negative experiences. Some responders reported feeling abandoned (especially at the beginning of the pandemic), fearful and overwhelmed because of poor support from primary care (many GPs appeared unaware of the Long COVID service) and little understanding by the community (medical and workplace, especially) of living with Long COVID. The analysis of additional questionnaire answers from responders who did not get access to the Long COVID service reinforced the theme of feeling neglected and ignored by the healthcare system, with people having to find alternative ways to find help (e.g. private healthcare and social media support groups).
- Some responders reported that it took them a very long time to access the Long COVID service (although it was not possible to establish whether this was because the service was not available yet or because of delays in getting referral/access to services). Others underlined the lack of support tailored around their specific clinical needs. There were also questions about what would happen after being discharged from the service. Some responders requested to increase the frequency of appointments, and to make them face-to-face whenever possible, to enhance electronic communication, simplify referral, keep service users in the loop (even if discharged) and 'publicise' the existence of the service in the rest of the healthcare community and more widely.
- An interim 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 SROI was calculated as a ratio greater than 1, meaning that for every £1 invested there is a social return of 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 being 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 the latest 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, which allocated £5 million to the seven Welsh Local Health Boards (LHBs)¹ in September 2021. Its purpose was 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) plans to review 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. For this purpose, WG requested each LHB to provide information by the 14th of January 2022 on how they have been locally implementing the programme, and whether it is making a positive difference to those suffering with Long COVID symptoms. It should be noted that to have an allocation of funding in September 2021 and then to recruit staff and establish services, has required significant effort and pace. Therefore, this January 2022 report should be considered as interim, as not all LHBs have been delivering a full service for 6 months.

The Executive Directors of Therapies and Health Science collectively supported and commissioned a national approach to evaluation.

Following this request, Cedar Health Technology Research Centre (<https://cedar.nhs.wales/>) and the Welsh Value in Health Centre (WViHC, <https://vbhc.nhs.wales/>) have been supporting LHBs by facilitating data collection from their Long COVID service users, and by providing data analysis, reporting and summarising.

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 3.1). Data was collected from four groups of Long COVID service users in Wales, with the final aim to report 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 1 st of September 2021
New referrals	New referrals post 1 st 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 6 th of September 2021 and the 31 st of December

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 additional economic evaluation of their Long COVID Rehabilitation service. An interim report was produced using the approach of Social Return of Investment and is summarised in this report (Sections

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)



2.2 and 3.2). However additional data collection is still ongoing and the full report will be completed in March 2022.

Finally, in order to provide further context, information collected from each LHB is also presented at the end of this report. This includes definitions of those allowed access to the Long COVID service, and the number of people who have been accessing the service so far (Sections 2.3 and 3.3).

2 Methods

2.1 National service user questionnaire data collection

The data was collected from the 1st of September 2021 to the 31st of December 2021 via secure web questionnaires set up by Cedar and administered by LHBs to 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). Their data was then provided to Cedar at the end of the collection period.

A combination of twenty-four 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 services. 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 for the 'New referrals' group.

Questionnaire section	Questions (Q)	Description	Administered to
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 COVID-19 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, information governance issues meant that it was not possible to request identifiable data. As the questionnaire responses were anonymous it was not possible to link data across the four service user groups (for example, if the same person answered a questionnaire at multiple time points, such as an 'existing service user' and

then being 'discharged' from the service). Thus, each group was considered as a cross-section in all the reported analyses, but some responders may be included in more than one group.

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 national service user questionnaire quantitative data

The responses from close-ended questions (except 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 national service user questionnaire 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 and percentages of themes per service user group were calculated using 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 being 'Positive feedback', 'Negative feedback' (specific to the service or not) or 'Suggestions for improvement'.

2.1.4 Data filtering

Some responses were excluded from the main questionnaire analysis 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 were also excluded if in the free text answers (Q19 and Q20) responders explicitly declared that they had not accessed the Long COVID service. The reasons for this are unclear, however one example was from those referred to the Long COVID service and still waiting to access the service but who had already been provided with a questionnaire link.

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. This 'additional' data was separately analysed for demographics (Q1-Q4), COVID Symptoms (Q6 and Q6a) and comments provided in the free text for Q19 and Q20.

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 interim SROI report, and data collection is ongoing. The full report will be made available in March 2022.

2.3 Local Health Boards data collection

Additional related data was collected from each LHB via a questionnaire to identify the definitions of Long COVID used for service referral, to quantify the number of service users and the types of services provided. Since this data was heterogeneous (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 and percentages.



3 Results

3.1 National service user questionnaire results

The survey included a total of 760 responses and 589 (77.5%) of these were retained in the main analysis (see Section 2.1.4), which includes Sections from 3.1.1 to 3.1.7. The remaining 171 (22.5%) additional responses were analysed separately in Section 3.1.8.

3.1.1 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 their employment status in Figure 3.

The largest group was 'New referrals' (n=295), while the 'Follow-up' group was the smallest (n=32). The largest number of responders of the 'Existing service users' group were from C&V UHB (34.5%), while for 'New referrals', 'Follow-up' and 'Discharge' they were from CTM UHB (50.8%, 65.6% and 59%, respectively). In all four service user groups: the majority were women, the most frequent age range was 51-60, most of the responders were of White ethnic background and the most frequent employment description was 'working full-time'.

		Existing service users	New referrals	Follow-up	Discharge	Totals
Number of responders		223 (100%)	295 (100%)	32 (100%)	39 (100%)	589 (100%)
Health Board	AB UHB	19 (8.5%)	11 (3.7%)	0 (0%)	0 (0%)	30 (5.1%)
	BC UHB	0 (0%)	3 (1%)	0 (0%)	0 (0%)	3 (0.5%)
	C&V UHB	77 (34.5%)	26 (8.8%)	1 (3.1%)	1 (2.6%)	105 (17.8%)
	CTM UHB	72 (32.3%)	150 (50.8%)	21 (65.6%)	23 (59%)	266 (45.2%)
	HD UHB	0 (0%)	63 (21.4%)	0 (0%)	1 (2.6%)	64 (10.9%)
	PT HB	16 (7.2%)	9 (3.1%)	3 (9.4%)	0 (0%)	28 (4.8%)
	SB UHB	39 (17.5%)	33 (11.2%)	7 (21.9%)	14 (35.9%)	93 (15.8%)
Gender	Female	161 (72.2%)	179 (63.9%)	21 (65.6%)	26 (66.7%)	387 (65.7%)
	Male	62 (27.8%)	99 (35.4%)	11 (34.4%)	13 (33.3%)	185 (31.4%)
	Non-Binary	0 (0%)	1 (0.4%)	0 (0%)	0 (0%)	1 (0.2%)
	Prefer not to say	0 (0%)	1 (0.4%)	0 (0%)	0 (0%)	1 (0.2%)
Age range	17 and under	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
	18 - 30	17 (7.6%)	15 (5.1%)	0 (0%)	2 (5.1%)	34 (5.8%)
	31 - 40	26 (11.7%)	48 (16.3%)	2 (6.2%)	2 (5.1%)	78 (13.2%)
	41 - 50	58 (26%)	71 (24.1%)	10 (31.2%)	7 (17.9%)	146 (24.8%)
	51 - 60	75 (33.6%)	97 (32.9%)	12 (37.5%)	14 (35.9%)	198 (33.6%)
	61 - 70	39 (17.5%)	46 (15.6%)	6 (18.8%)	11 (28.2%)	102 (17.3%)
	71 - 80	7 (3.1%)	17 (5.8%)	2 (6.2%)	3 (7.7%)	29 (4.9%)
	81 - 90	1 (0.4%)	1 (0.3%)	0 (0%)	0 (0%)	2 (0.3%)
Language used to respond	91 and over	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
	English	222 (99.6%)	294 (99.7%)	32 (100%)	39 (100%)	587 (99.7%)
	Welsh	1 (0.4%)	1 (0.3%)	0 (0%)	0 (0%)	2 (0.3%)

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



Existing service users

N responders = 222 (99.6% of total group responders)

Any White background	215(96.8%)
White and Black Caribbean	1(0.5%)
Pakistani	1(0.5%)
Bangladeshi	1(0.5%)
Any other Asian background	1(0.5%)
African	1(0.5%)
Any other ethnic group	1(0.5%)
Prefer not to say	1(0.5%)
Gypsy or Irish Traveller	0(0%)
White and Black African	0(0%)
White and Asian	0(0%)
Any other mixed background/ multiple ethnic background	0(0%)
Indian	0(0%)
Chinese	0(0%)
Caribbean	0(0%)
Any other Black background	0(0%)
Arab	0(0%)

Follow-up

N responders = 32 (100% of total group responders)

Any White background	30(93.8%)
White and Asian	1(3.1%)
Any other Asian background	1(3.1%)
Gypsy or Irish Traveller	0(0%)
White and Black Caribbean	0(0%)
White and Black African	0(0%)
Any other mixed background/ multiple ethnic background	0(0%)
Indian	0(0%)
Pakistani	0(0%)
Bangladeshi	0(0%)
Chinese	0(0%)
Caribbean	0(0%)
African	0(0%)
Any other Black background	0(0%)
Arab	0(0%)
Any other ethnic group	0(0%)
Prefer not to say	0(0%)

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.

New referrals

N responders = 260 (88.1% of total group responders)

Any White background	251(96.5%)
Any other mixed background/ multiple ethnic background	2(0.8%)
Any other Asian background	2(0.8%)
White and Black African	1(0.4%)
White and Asian	1(0.4%)
Indian	1(0.4%)
Any other ethnic group	1(0.4%)
Prefer not to say	1(0.4%)
Gypsy or Irish Traveller	0(0%)
White and Black Caribbean	0(0%)
Pakistani	0(0%)
Bangladeshi	0(0%)
Chinese	0(0%)
Caribbean	0(0%)
African	0(0%)
Any other Black background	0(0%)
Arab	0(0%)

Discharge

N responders = 38 (97.4% of total group responders)

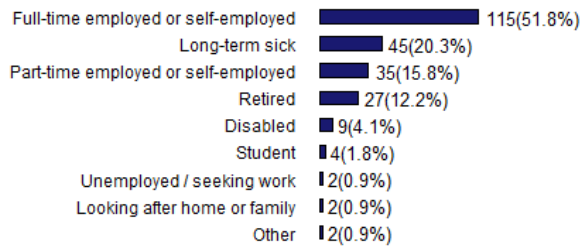
Any White background	37(97.4%)
Prefer not to say	1(2.6%)
Gypsy or Irish Traveller	0(0%)
White and Black Caribbean	0(0%)
White and Black African	0(0%)
White and Asian	0(0%)
Any other mixed background/ multiple ethnic background	0(0%)
Indian	0(0%)
Pakistani	0(0%)
Bangladeshi	0(0%)
Chinese	0(0%)
Any other Asian background	0(0%)
Caribbean	0(0%)
African	0(0%)
Any other Black background	0(0%)
Arab	0(0%)
Any other ethnic group	0(0%)

Figure 2. Bar plots for: [Q3] "Please tell us your ethnicity". Data for 'New referrals' and 'Discharge' service user groups. The numbers at the end of each bar indicate number of responders and percentage for each answer option within each group.



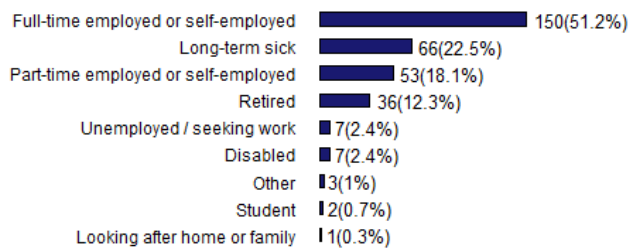
Existing service users

N responders = 222 (99.6% of total group responders)



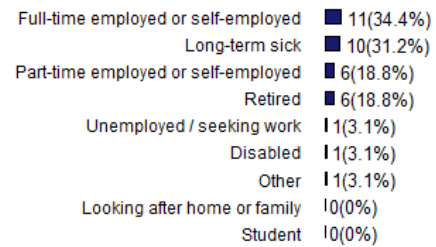
New referrals

N responders = 293 (99.3% of total group responders)



Follow-up

N responders = 32 (100% of total group responders)



Discharge

N responders = 36 (92.3% of total group responders)

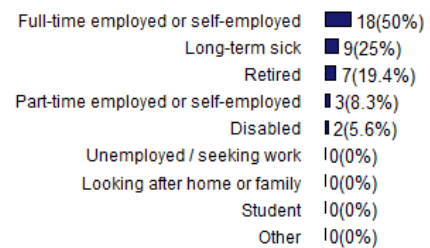


Figure 3. Bar plots for: [Q4] "Which of these definitions describe your employment status?" Multiple responses per participant were allowed for this question (i.e., for each bar, 100% would represent all responders within the group chose that option).



3.1.2 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. The 'Discharge' group had the highest percentage of admitted service users (26.3%), closely followed by the 'Follow-up' group (25%) the 'Existing service users' group (24%) and the 'New referrals' group (18.5%).

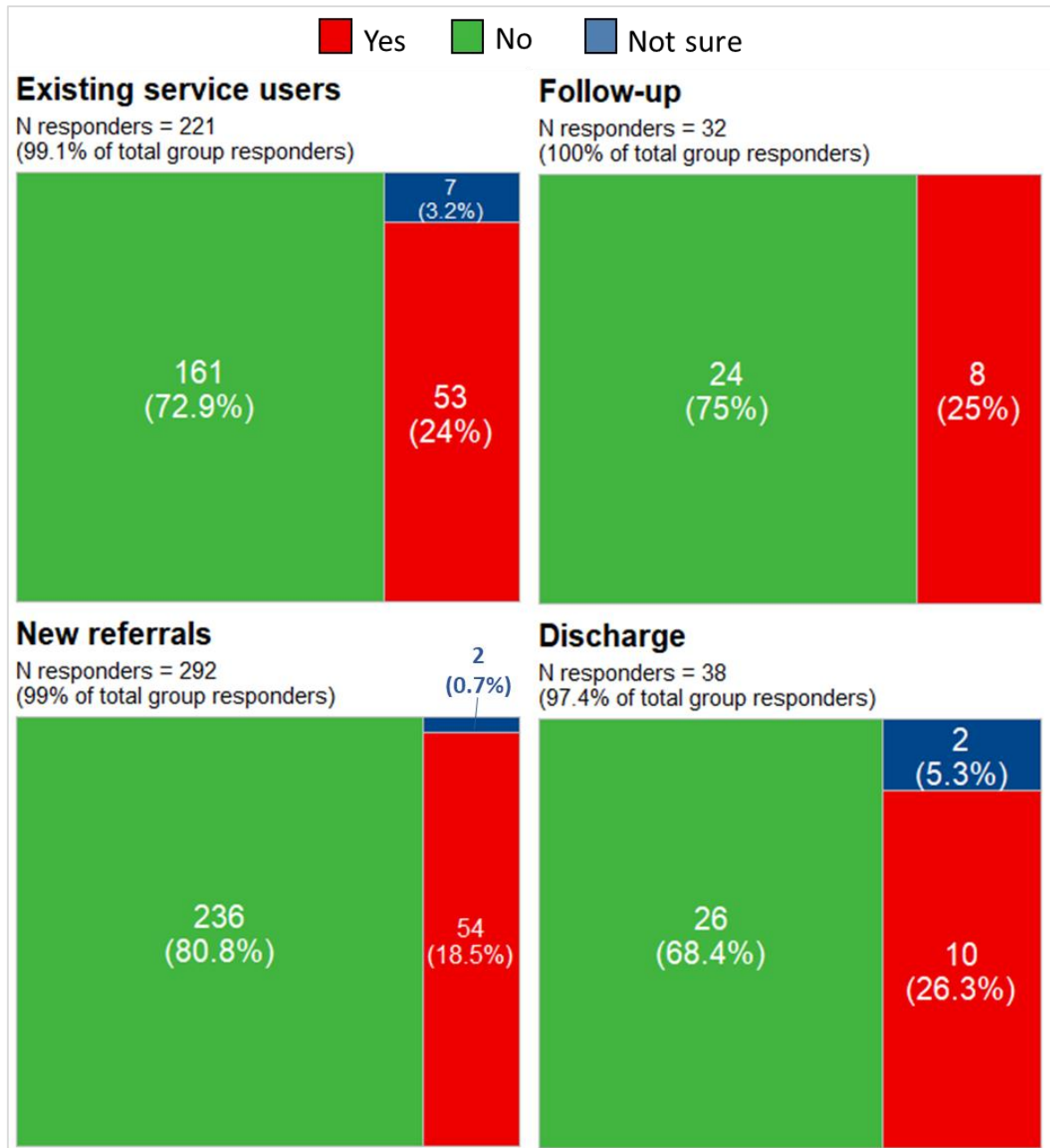


Figure 4. Tree map plot for: [Q5] "Have you been admitted to hospital as an in-patient as a result of COVID-19?" The numbers in the coloured areas indicate number of responders and percentage for each answer option within each service user group.



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 'Follow-up' group spent a median of 36 days in hospital, the 'Discharge' groups 20 days, the 'Existing service users' 9 days, and the 'New referrals' group 4 days.

	Existing service users	New referrals	Follow-up	Discharge
Number of responders	52	52	8	7
% who responded to the question	23.30%	17.60%	25%	17.90%
Minimum value	0	0	1	3
Median (IQR)	9 (5,21.8)	4 (1,14.2)	36 (6.8,54.8)	20 (12.5,66)
Maximum value	95	182	85	106

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.

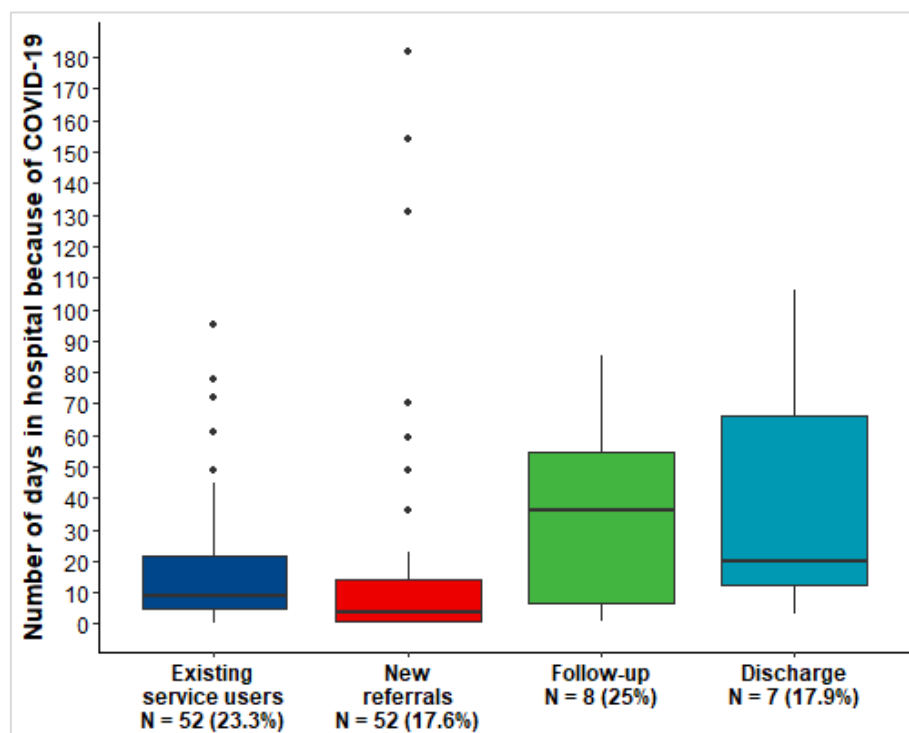


Figure 5. Box plots for [Q5a]: "(If you answered 'Yes' to Q5) In total, how many days did you spend in hospital because of COVID-19? (If you are still in hospital, please tell us how many days you have been in hospital so far)". For each service user group, number of responders (N) and the % of total group responders are reported under the group label

3.1.3 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 from the 'Existing service users' (91%), 'New referrals' (88.4%) and 'Follow-up' (84.4%) groups, while 'Shortness of breath' was the most common in the 'Discharge' group (74.4%). Other frequent symptoms (> 50%) were 'Brain fog', 'Joint pain', 'Insomnia' and 'Depression and anxiety'.

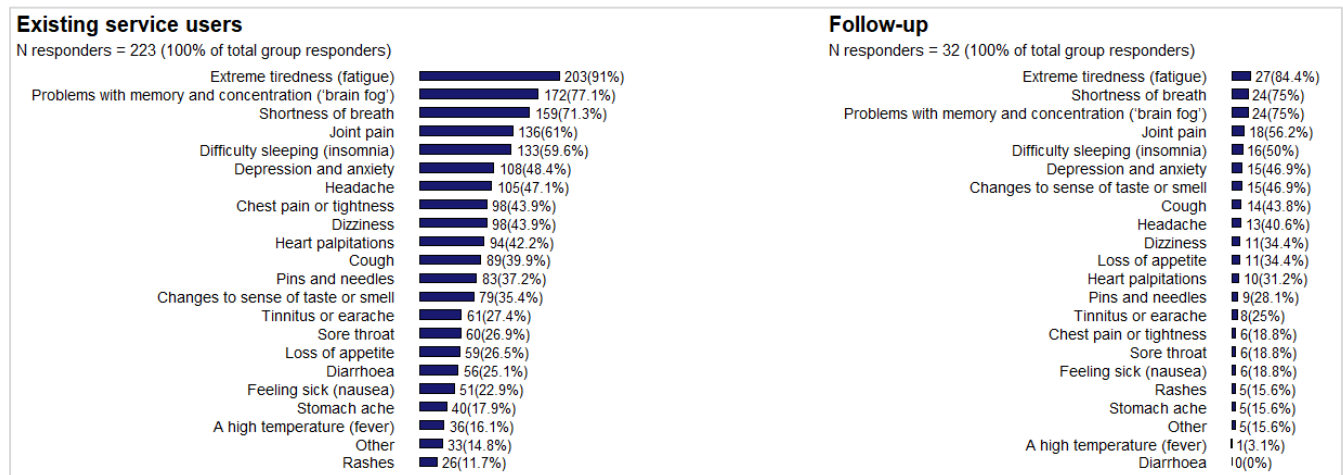


Figure 6. Bar plots for [Q6]: "Please tell us about any symptoms you have experienced today due to COVID-19". Data for 'Existing service users' and 'Follow-up' service user groups. Multiple responses per participant were allowed for this question (i.e., for each bar, 100% would represent that all responders within the group chose that option).

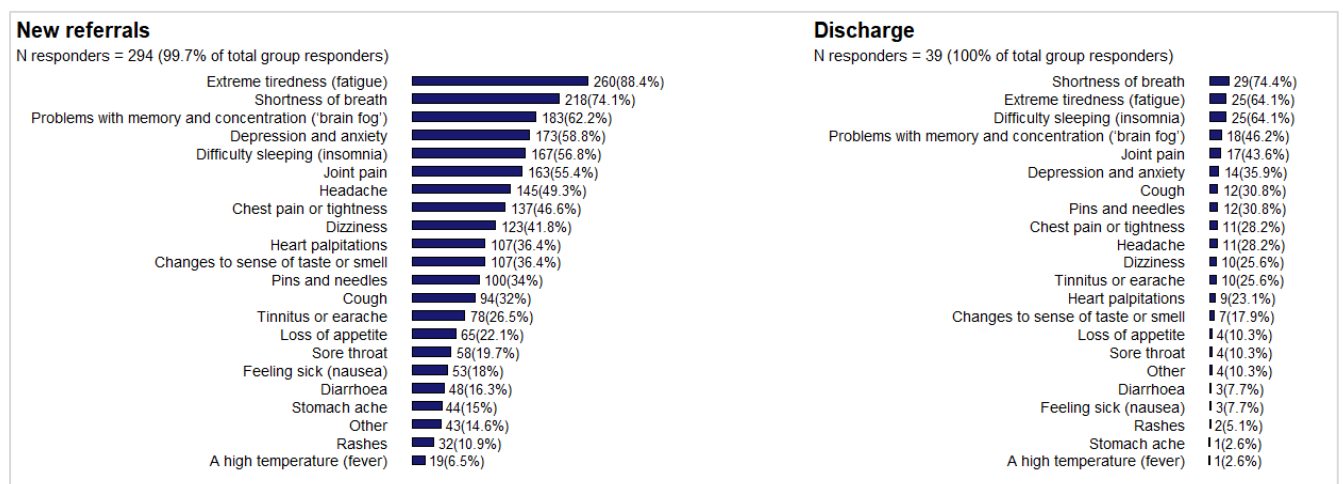


Figure 7. Bar plots for [Q6]: "Please tell us about any symptoms you have experienced today due to COVID-19". Data for 'New referrals' and 'Discharge' service user groups. Multiple responses per participant were allowed for this question (i.e., for each bar, 100% would represent that all responders within the group chose that option).

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 85 responders are summarised in Table 5. Service users most often mentioned 'Pain' of different kinds (e.g. muscle pain and general pain in the body as well as localised in specific areas), 'Mobility issues' (often due to leg issues), problems with their 'Voice, mouth, throat and/or swallowing' and various 'Vision and eye' issues.

OTHER SYMPTOMS	Existing service users N = 33 (14.8%)	New referrals N = 43 (14.6%)	Follow-up N = 5 (15.6%)	Discharge N = 4 (10.2%)
Pain (e.g. muscle pain/stiffness, general pain in the body, local pain to back, arm, chest, face or neck)	7 (21.2%)	14 (32.6%)	1 (20%)	1 (25%)
Mobility issues (including leg issues, balance issues)	6 (18.2%)	10 (23.3%)	0 (0%)	1 (25%)
Voice, mouth, throat and swallow issues	3 (9.1%)	6 (14%)	3 (60%)	0 (0%)
Vision and eye issues	7 (21.2%)	4 (9.3%)	0 (0%)	0 (0%)
Excessive sweating/feeling hot and/or inability to regulate body temperature	3 (9.1%)	6 (14%)	0 (0%)	1 (25%)
Hair loss	3 (9.1%)	4 (9.3%)	0 (0%)	0 (0%)
Bladder issues (e.g. inflammation and incontinence)	1 (3%)	3 (7%)	0 (0%)	1 (25%)
Cardiovascular issues (e.g. tachycardia)	3 (9.1%)	1 (2.3%)	0 (0%)	0 (0%)
Hypersensitivity (e.g. to light, sound, pain or skin hypersensitivity)	1 (3%)	3 (7%)	0 (0%)	0 (0%)
Involuntary tremor	0 (0%)	4 (9.3%)	0 (0%)	0 (0%)
Issues with feet and hands (cold, sore)	2 (6.1%)	1 (2.3%)	0 (0%)	0 (0%)
Gastrointestinal issues	1 (3%)	2 (4.7%)	0 (0%)	0 (0%)
Sinus issues	2 (6.1%)	1 (2.3%)	0 (0%)	0 (0%)
Speech production or understanding issues	1 (3%)	2 (4.7%)	0 (0%)	0 (0%)
Falling	1 (3%)	0 (0%)	1 (20%)	0 (0%)
Lung issues	0 (0%)	2 (4.7%)	0 (0%)	0 (0%)
Menstrual issues	1 (3%)	1 (2.3%)	0 (0%)	0 (0%)
Numbness of body (e.g. feet, face)	2 (6.1%)	0 (0%)	0 (0%)	0 (0%)
Reflux	2 (6.1%)	0 (0%)	0 (0%)	0 (0%)
Weight gain	0 (0%)	1 (2.3%)	0 (0%)	1 (25%)
Swollen glands	0 (0%)	0 (0%)	1 (20%)	0 (0%)
Hearing loss	1 (3%)	0 (0%)	0 (0%)	0 (0%)
Hiatus hernia	0 (0%)	1 (2.3%)	0 (0%)	0 (0%)
Hyperventilating as a result of exposure to fresh air	0 (0%)	1 (2.3%)	0 (0%)	0 (0%)
Lower immunity	1 (3%)	0 (0%)	0 (0%)	0 (0%)
Panic attacks	0 (0%)	1 (2.3%)	0 (0%)	0 (0%)
Post-exertional malaise	0 (0%)	1 (2.3%)	0 (0%)	0 (0%)
Phlegm at night	1 (3%)	0 (0%)	0 (0%)	0 (0%)
Excessive thirst	1 (3%)	0 (0%)	0 (0%)	0 (0%)
Vertigo	1 (3%)	0 (0%)	0 (0%)	0 (0%)

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



3.1.4 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 'Follow-up' group had a median of 5 GP sessions, while the other groups had 4.

	Existing service users	New referrals	Follow-up	Discharge
Number of responders	216	287	30	32
% who responded to the question	96.90%	97.30%	93.80%	82.10%
Minimum value	0	0	1	0
Median (IQR)	4 (2,7)	4 (2,6)	5 (3,6.8)	4 (2,5)
Maximum value	20	100	20	12

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.

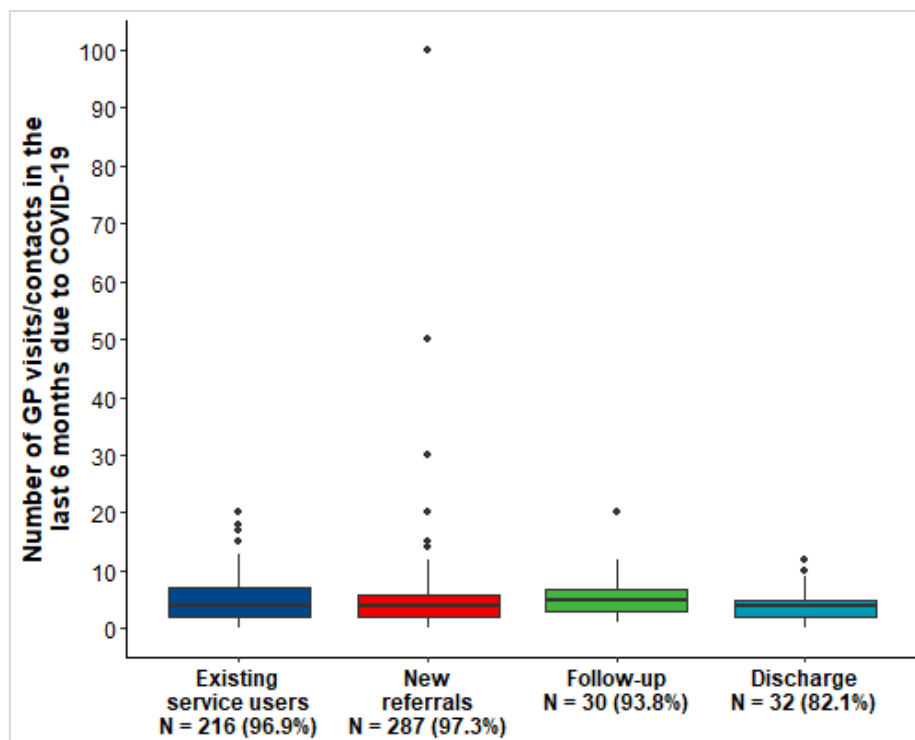


Figure 8. Box plots for: [Q7] "Please tell us how many GP visits/contacts (face-to-face or remotely) you have had in the last 6 months related to COVID-19". For each service user group, number of responders (N) and the % of total group responders are reported under the group label



3.1.5 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' group had a median of 6 rehabilitation sessions, the 'Discharge' group had 5, 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	187	242	28	30
% who responded to the question	83.90%	82%	87.50%	76.90%
Minimum value	0	0	0	0
Median (IQR)	3 (1,6)	1 (0,1)	6 (3.8,10)	5 (2.2,8.5)
Maximum value	20	24	40	21

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.

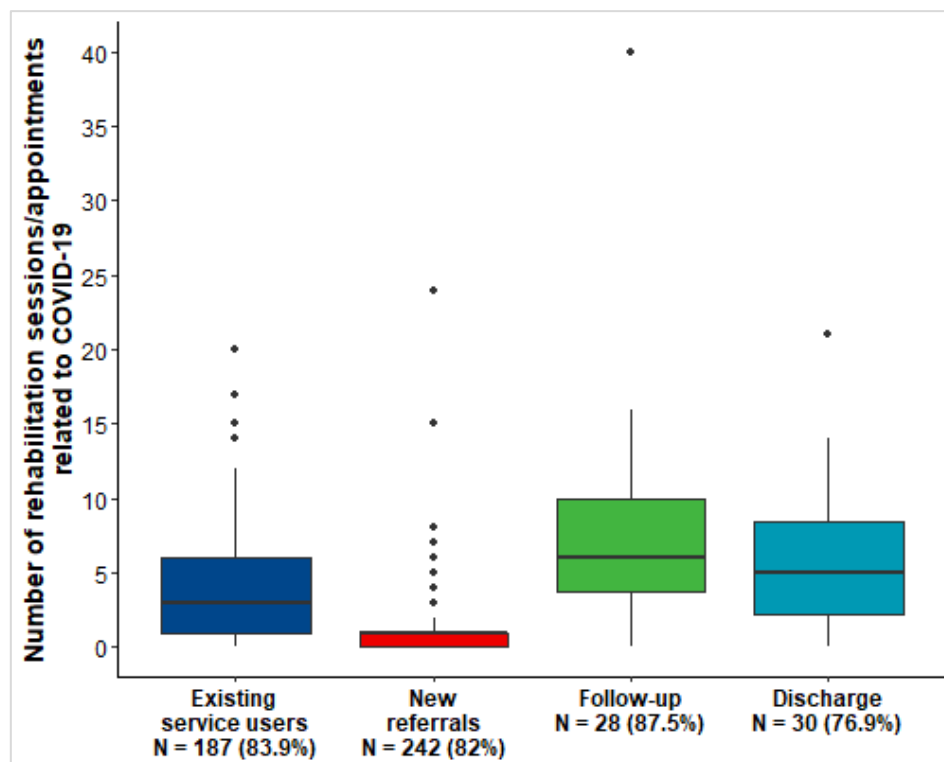


Figure 9. Box plots for: [Q8] If you have had rehabilitation related to your COVID-19, please tell us how many sessions/appointments you have had. For each service user group, number of responders (N) and the % of total group responders are reported under the group label



3.1.6 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.

In the 'Discharge' and 'Follow-up' groups, more responders answered with 'I have no problems in walking about' than any other answer option for the 'mobility' dimension (41% and 31.2%, respectively). While in the 'New referrals' and 'Existing service users' groups, 'I have moderate problems in walking about' was the most frequent answer option (34.5% and 33.6%, respectively). In all groups, < 5% of responders chose the most severe option (score = 5) 'I am unable to walk about'.

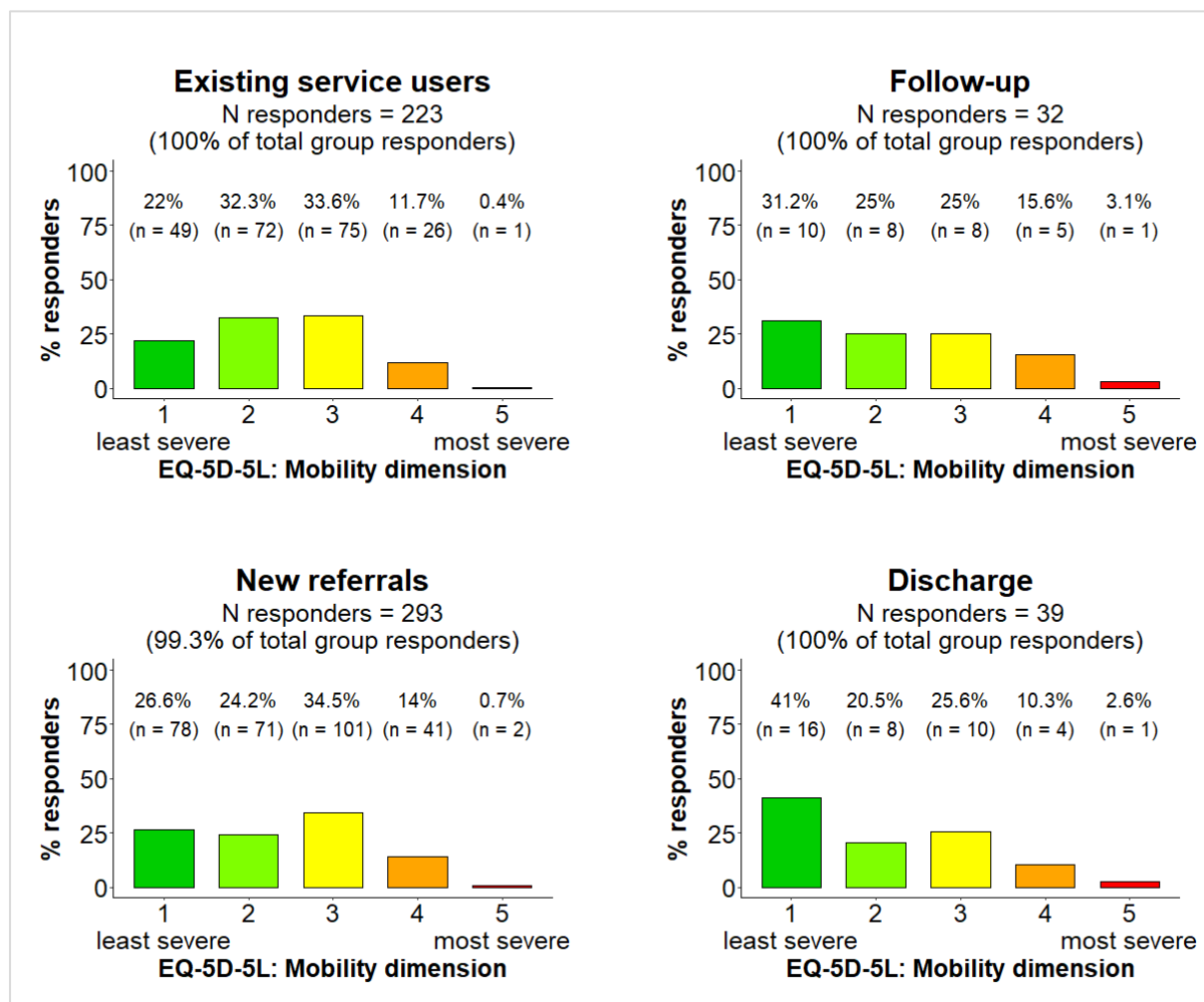


Figure 10. % Bar plots for: [Q9] "Please select the option that best describes your health TODAY: MOBILITY".

N = number of responders for each service user group. n = number of group responders that chose the specific EQ-5D-5L dimension score.



For the 'self-care' dimension (Figure 11), the majority of responders in all groups chose the option 'I have no problems washing or dressing myself' (score = 1; 62.5% of 'Follow-up' group, 61.5% of 'Discharge', 56.8% of 'New referrals' and 53.8% of 'Existing service users').

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

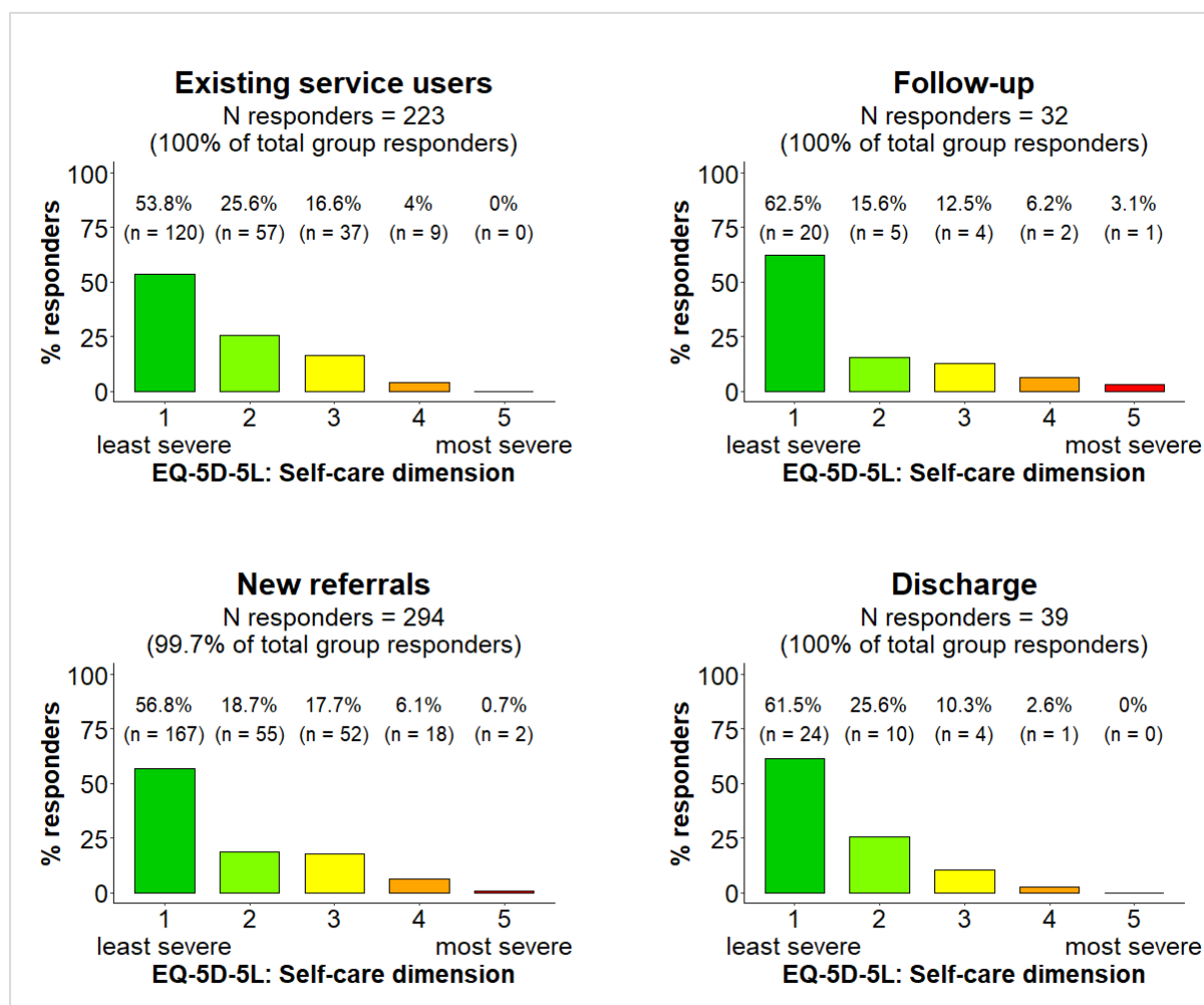


Figure 11. % Bar plots for: [Q10] "Please select the option that best describes your health TODAY: SELF-CARE". N = number of responders for each service user group. n = number of group responders that chose the specific EQ-5D-5L dimension score.

In the 'Existing service users', 'New referrals' and 'Follow-up' groups, more responders answered with 'I have moderate problems doing my usual activities' than any other answer option for the 'usual activities' dimension (37.2%, 34.1% and 31.2%, respectively). While In the 'Discharge' group, both 'I have slight problems' and "I have moderate problems" were the most frequent answer options (35.9%).

Nine percent or more of responders in each group chose the most severe option (score = 5) 'I am unable to do my usual activities' (16% of 'New referrals', 15.6% of 'Follow-up', 10.3% of 'Discharge' and 9% of 'Existing service users').

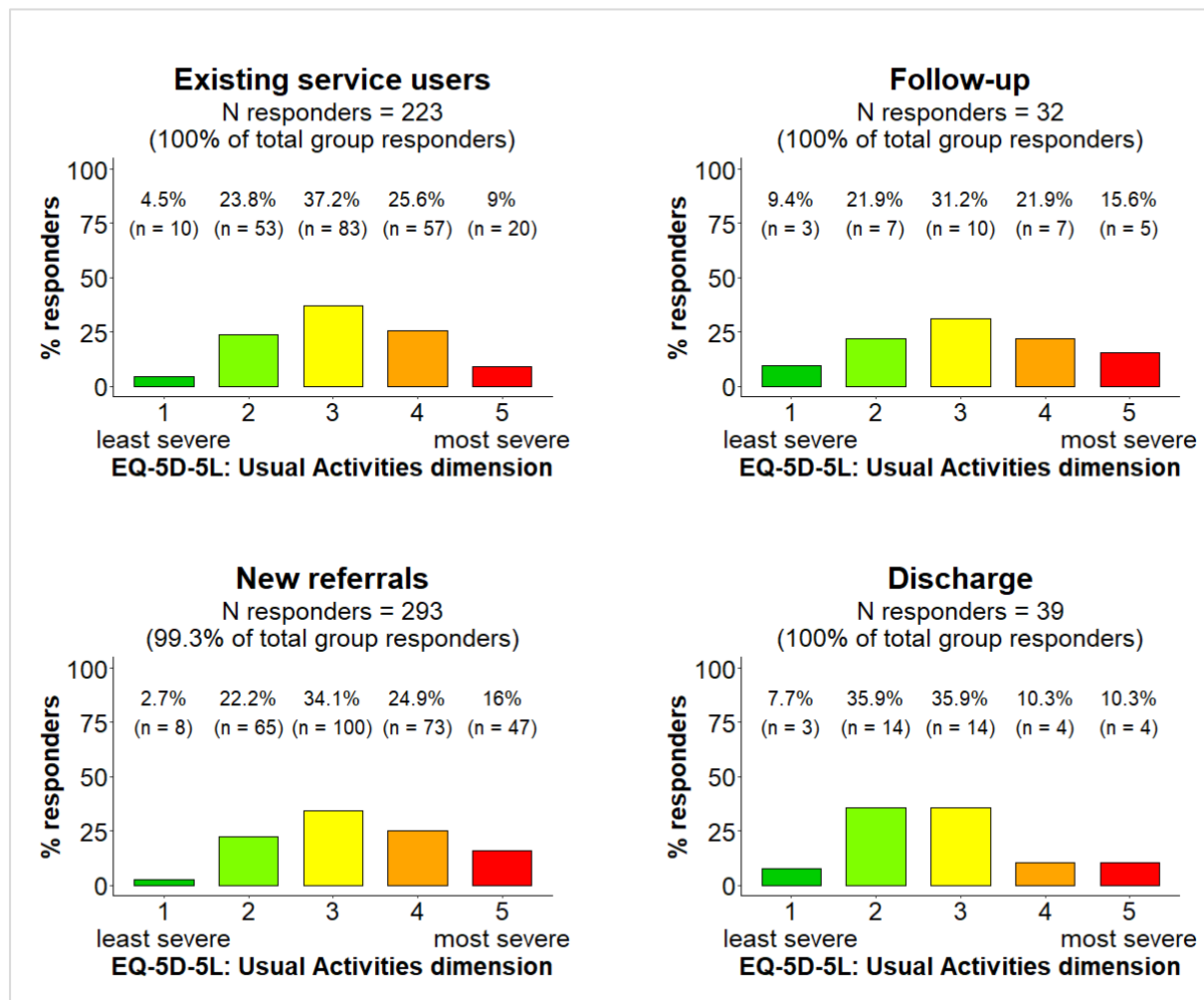


Figure 12. % Bar plots for: [Q11] "Please select the option that best describes your health TODAY: USUAL ACTIVITIES". N = number of responders for each service user group. n = number of group responders that chose the specific EQ-5D-5L dimension score.



In the 'Existing service users', 'New referrals' and 'Follow-up' groups, more responders answered with 'I have moderate pain or discomfort' than any other answer option for the 'pain and discomfort' dimension (38.6%, 36.5% and 34.4%, respectively). While In the 'Discharge' group, 'I have slight pain or discomfort' was the most frequent answer option (41%).

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

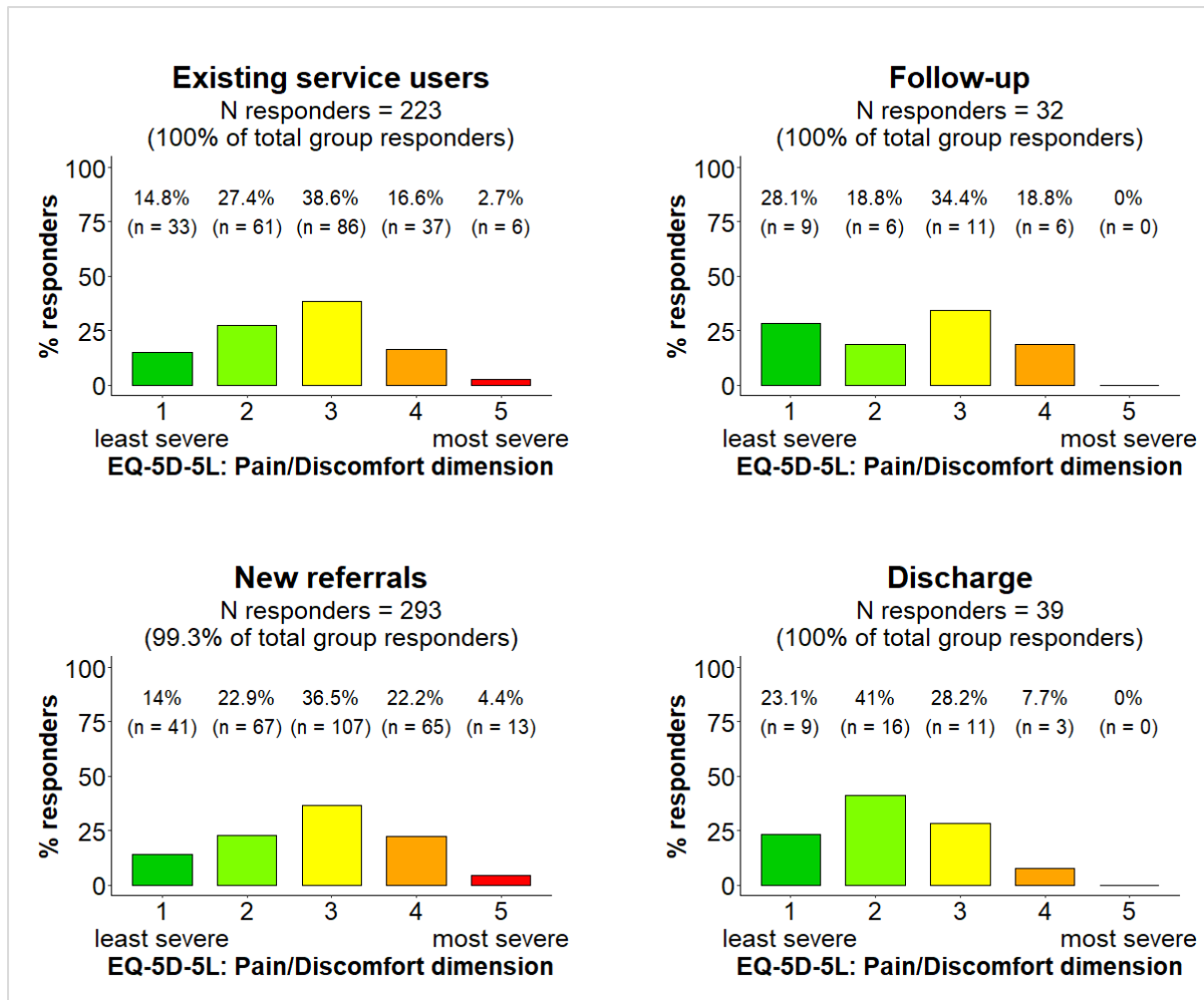


Figure 13. % Bar plots for: [Q12] "Please select the option that best describes your health TODAY: PAIN & DISCOMFORT". N = number of responders for each service user group. n = number of group responders that chose the specific EQ-5D-5L dimension score.



In the 'Follow-up', 'Discharge' and 'Existing service users' groups, more responders answered with 'I am slightly anxious or depressed' than any other answer option for the 'anxiety and depression' dimension (43.8%, 35.9% and 34.1%, respectively). While In the 'New referrals' group, 'I am moderately anxious or depressed' was the most frequent answer option (35.8%).

Above 5% of responders in the 'Discharge' (5.1%) and 'Follow-up' (6.2%) groups chose the most severe option (score = 5) 'I am extremely anxious or depressed'.

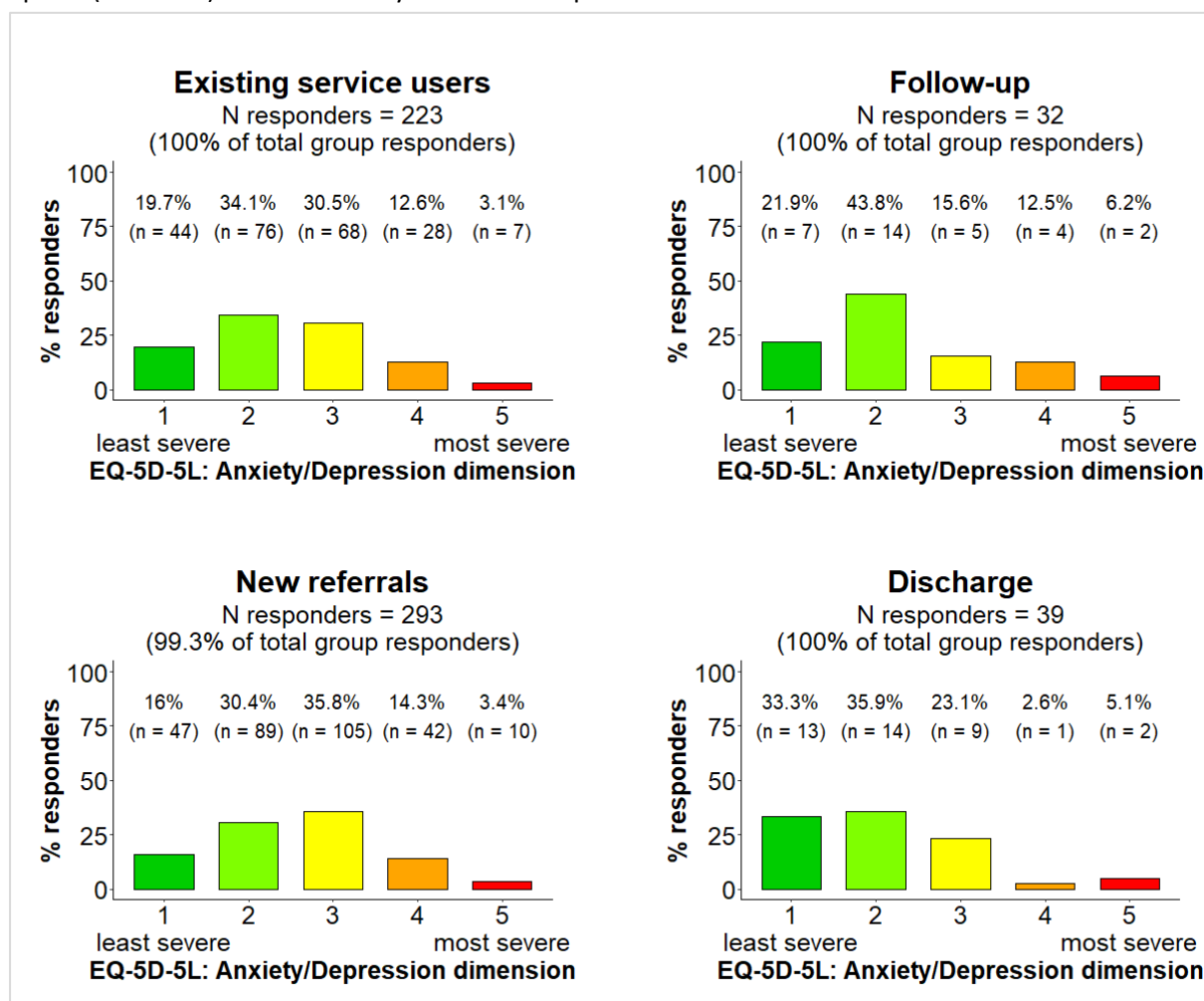


Figure 14. % Bar plots for: [Q13] "Please select the option that best describes your health TODAY: ANXIETY & DEPRESSION". N = number of responders for each service user group. n = number of group responders that chose the specific EQ-5D-5L dimension score.



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 highest median EQ-5D-5L index was for the 'Discharge' group (0.67), and the lowest for the 'New referrals' (0.53).

The statistical distributions of EQ-5D-5L index were significantly different across the four service user cohorts (Kruskal-Wallis test: $H(3) = 10.493$, $p = 0.015$). Those in the 'Discharge' group tended to have a higher EQ-5D-5L index (i.e. better quality of life) in comparison to 'New referrals' ($p = 0.016$).

	Existing service users	New referrals	Follow-up	Discharge
Number of responders	223	292	32	39
% for whom EQ-5D-5L Index was calculated	100%	99%	100%	100%
Minimum value	-0.283	-0.352	-0.248	-0.024
Median (IQR)	0.54 (0.3,0.7)	0.53 (0.2,0.7)	0.65 (0.3,0.8)	0.67 (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.

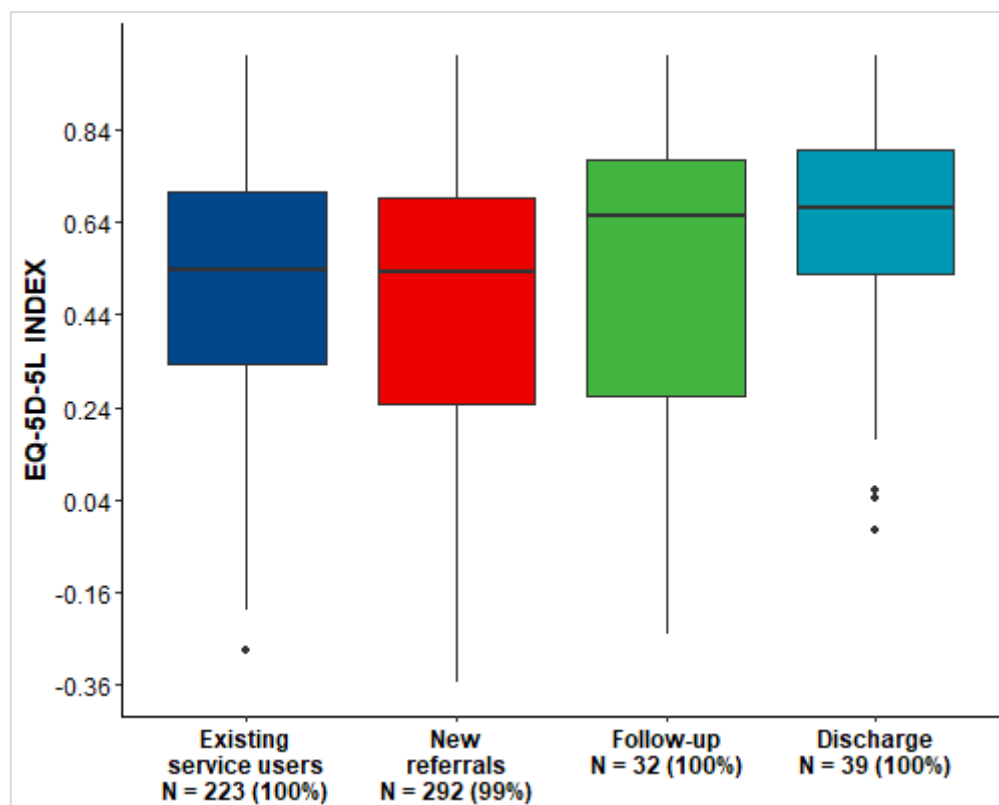


Figure 15. Box plots for: EQ-5D-5L index. Calculated from EQ-5D-5L scores [Q9]-[Q13]. For each service user group, number of responders (N) and the % of total group responders are reported under the group label



EQ-VAS results are reported for each group in Table 9 and Figure 16. The highest median EQ-VAS was 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: $H(3) = 18.449$, $p < 0.001$). Those in the 'Discharge' group tended to have a higher EQ-VAS (indicating a higher quality of life) in comparison to 'Existing service users' ($p = 0.005$) and 'New referrals' ($p < 0.001$).

	Existing service users	New referrals	Follow-up	Discharge
Number of responders	223	293	32	39
% who responded the question	100%	99.30%	100%	100%
Minimum value	0	0	0	20
Median (IQR)	50 (40,70)	50 (30,65)	50 (40,71.2)	65 (50,80)
Maximum value	95	100	100	95

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.

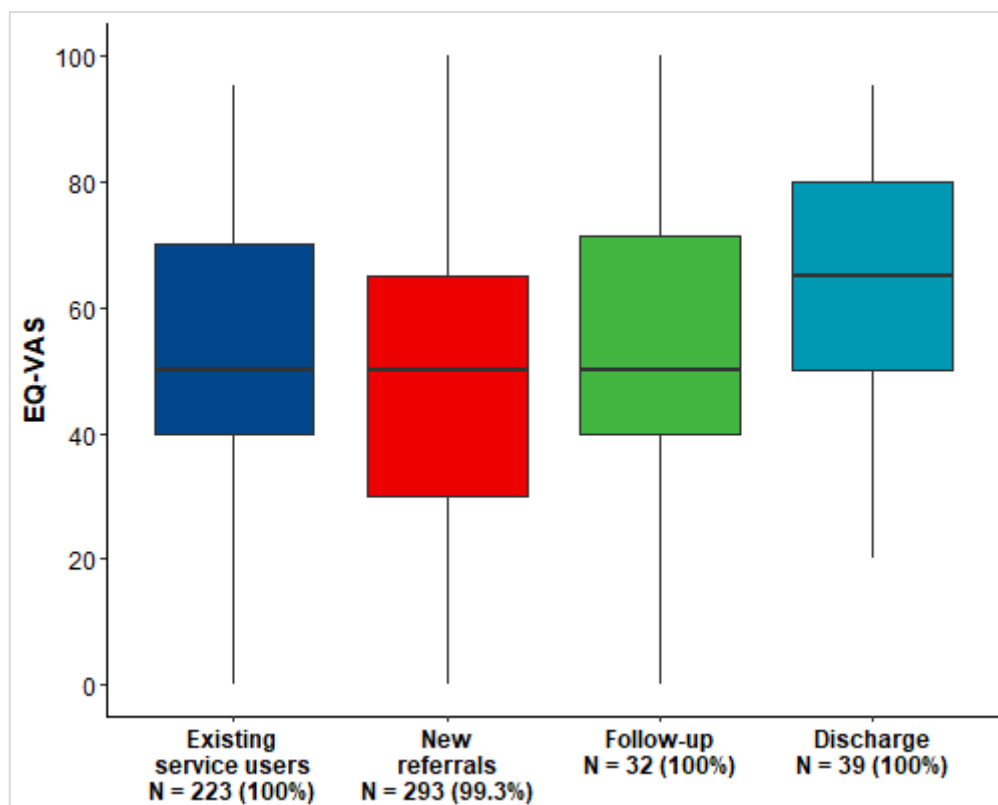


Figure 16. Box plots for: [Q14] "We would like to know how good or bad your health is today (scale 0-100)".

For each service user group, number of responders (N) and the % of total group responders are reported under the group label



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

Responders were asked about their experiences with the Long COVID service. This section does not include responses from the 'New referrals' group given their interaction with the service was assumed to be minimal.

Results for specific aspects of responders' experience (feeling listened to and understood, being supported to get the information they need and being involved in the support they received) are reported in Tables 10-12. From these answers, more than 60% of responders from the 'Follow-up' and 'Discharge' groups and about a half of the 'Existing service users' appeared very satisfied with the support they received.

When asked whether they felt 'their concerns were listened to and understood' (Table 10), most of the responders chose 'Always' ('Discharge' group: 78.9%; 'Follow-up' group: 71.9% and 'Existing service users' group: 50.9%). The second most selected option was 'Sometimes' ('Existing service users' group: 25%; 'Follow-up' group: 21.9%; 'Discharge' group: 10.5%).

Did you feel your concerns were listened to and understood?	Existing service users N = 216(96.9%)	Follow-up N = 32(100%)	Discharge N = 38(97.4%)
Always	110 (50.9%)	23 (71.9%)	30 (78.9%)
Usually	27 (12.5%)	2 (6.2%)	1 (2.6%)
Sometimes	54 (25%)	7 (21.9%)	4 (10.5%)
Never	25 (11.6%)	0	3 (7.9%)

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



When asked whether they were supported 'to get the information and help they needed' (Table 11), the majority of the responders chose 'Always' ('Discharge' group: 71.1%; 'Follow-up' group: 62.5% and 'Existing service users' group: 50.2%). The second most selected option was either 'Sometimes' ('Existing service users' group: 22.6%; 'Discharge' group: 21.1%) or 'Usually' ('Follow-up' group: 18.8%).

Were you supported to get the information and help you needed?	Existing service users N = 217(97.3%)	Follow-up N = 32(100%)	Discharge N = 38(97.4%)
Always	109 (50.2%)	20 (62.5%)	27 (71.1%)
Usually	33 (15.2%)	6 (18.8%)	3 (7.9%)
Sometimes	49 (22.6%)	5 (15.6%)	8 (21.1%)
Never	26 (12%)	1 (3.1%)	0

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



When asked whether they were 'involved enough in deciding what support they received' (Table 12), the most frequent answer option in the 'Discharge', 'Follow-up' and 'Existing service users' groups was 'always' (71.1%, 64.5% and 49.8%, respectively). The next most frequent answer was 'Sometimes' for the 'Follow-up' group (16.1%), and 'Never' for the 'Existing service users' and 'Discharge' groups (18.6% and 13.2%, respectively).

Were you involved enough in deciding what support you received?	Existing service users N = 215(96.4%)	Follow-up N = 31(96.9%)	Discharge N = 38(97.4%)
Always	107 (49.8%)	20 (64.5%)	27 (71.1%)
Usually	30 (14%)	4 (12.9%)	2 (5.3%)
Sometimes	38 (17.7%)	5 (16.1%)	4 (10.5%)
Never	40 (18.6%)	2 (6.5%)	5 (13.2%)

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



Considering their overall 'Long COVID service experience' (Table 13), more than 70% of the responders provided an above average rate (>5): 81.3% of the 'Follow-up' group, 80.6% of the 'Discharge' group and 70.2% of the 'Existing service users'. Looking at the negative end of the scale, 20.2% of the 'Existing service users' rated their experience as < 5, while only 13.9% of the 'Discharge' and 12.5% of the 'Follow-up' group responders did the same.

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 = 218(97.8%)	Follow-up N = 32(100%)	Discharge N = 36(92.3%)
0 (Very bad)	9 (4.1%)	0	1 (2.8%)
1	9 (4.1%)	0	0
2	8 (3.7%)	0	2 (5.6%)
3	10 (4.6%)	3 (9.4%)	1 (2.8%)
4	8 (3.7%)	1 (3.1%)	1 (2.8%)
5 (Average)	21 (9.6%)	2 (6.2%)	2 (5.6%)
6	15 (6.9%)	1 (3.1%)	3 (8.3%)
7	23 (10.6%)	2 (6.2%)	0
8	26 (11.9%)	3 (9.4%)	5 (13.9%)
9	19 (8.7%)	2 (6.2%)	4 (11.1%)
10 (Excellent)	70 (32.1%)	18 (56.2%)	17 (47.2%)

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

A total of 239 responders (40.6% of total responders) provided further feedback in regards of their experiences via free text. Results were summarised by identifying core themes and representative quotes: Table 14 contains positive feedback for the Long COVID service, Table 15 and Table 16 contain negative feedback (specific for the service or not, respectively) and Table 17 contains suggestions for improvement.

Positive feedback highlighted how much responders valued feeling listened, acknowledged, understood and supported by the Long COVID service Teams. They also reported how much the information provided by the service has helped them in coping and improving with their condition and that the support was tailored around their needs. Responders also underlined the importance of having met other people affected by Long COVID via the service group sessions, making them feeling less lonely in their struggles.

Some responders expressed their gratitude towards specific healthcare staff members that looked after them.

Themes (Positive feedback)	Existing service users N = 177 (79.4%)	Follow-up N = 25 (78.1%)	Discharge N = 37 (94.9%)
Responders felt put at ease, listened to and acknowledged by the Long COVID team <ul style="list-style-type: none"> “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” 	50 (28.2%)	13 (52%)	13 (35.1%)

<ul style="list-style-type: none"> • <i>"Glad to have someone to talk to that understands and a safe place to talk. Really appreciate it"</i> • <i>"Personable and friendly, approachable, easy to open up to"</i> • <i>"All 3 professionals are kind, compassionate and validating that I've spoken to really helpful"</i> • <i>"I felt as though I was listened to and believed which was a huge positive for me"</i> • <i>"We have never felt alone during this difficult time"</i> 			
<p>Responders found the Long COVID service staff knowledgeable and the advice/treatment they provided helpful</p> <ul style="list-style-type: none"> • <i>"The presenters of the course were excellent and took their time to explain and listen"</i> • <i>"The [Long COVID service] staff really care and are learning constantly"</i> • <i>"They [Long COVID rehab team] have lots of knowledge"</i> • <i>"New techniques and advice so I can support myself"</i> • <i>"Feel more confident with information and contact"</i> • <i>"Helped me out, that's all I needed"</i> • <i>"Sent out useful information and explained things to me"</i> • <i>"[I was] given achievable strategies. [You were] telling me things I can understand"</i> • <i>"All aspects of the course were very helpful"</i> • <i>"It's the guidance you've given [...]. It's really helpful and relieved my symptoms"</i> • <i>"Helped relieve anxiety/worry. Excellent and supportive care and correct investigations"</i> • <i>"Everyone I've spoken to knowledgeable"</i> • <i>"I thought the course was very good"</i> • <i>"I found you to be helpful. Materials very helpful and useful. You're top class and helped me tremendously"</i> • <i>"All the advice, I have followed and makes so much sense and made such a huge difference. It's been great"</i> • <i>"Long COVID clinic [...] supportive and diagnosed my nerve damage"</i> • <i>"It's been lengthy and thorough, covered every angle. Has received some helpful advice"</i> • <i>"All the tips have been really helpful and I have felt better from following them"</i> • <i>"Given me the tools. If it wasn't for you, I've come so far. I'm so grateful"</i> 	32 (18.1%)	7 (28%)	11 (29.7%)
<p>Responders mentioned specific components of the Long COVID service that improved their recovery</p> <ul style="list-style-type: none"> • <i>"Explanation of breathing, videos how to breath properly, gives you back control"</i> • <i>"Breathing exercises helped 100%, feels better in 2 weeks"</i> • <i>"Pack that was sent was helpful and dry mouth samples sent by speech"</i> • <i>"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"</i> • <i>"The 'Managing Fatigue' course is very good"</i> • <i>"Useful speaking to the speech therapist, useful to understand and know what is going on"</i> • <i>"I have been supported emotionally as well as rehab for my mobility"</i> 	14 (7.9%)	7 (28%)	4 (10.8%)

<ul style="list-style-type: none"> • <i>"The meditation helps to take me out of my feelings"</i> • <i>"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"</i> • <i>"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"</i> • <i>"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"</i> • <i>"OT [Occupational Therapy] is amazing! Information and holistic OT support amazing."</i> 			
<p>Responders valued the group sessions, which allowed them to get mutual support, sharing and recognition from the interaction with other service users</p> <ul style="list-style-type: none"> • <i>"Good to speak to others who feel the same"</i> • <i>"Online sessions good with understanding people who shared their own experiences"</i> • <i>"Opportunity to talk to others in similar situations and to not feel alone"</i> • <i>"If we can help each other and have each other for support it makes such a big difference"</i> • <i>"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"</i> 	21 (11.9%)	0 (0%)	2 (5.4%)
<p>Responders felt the Long COVID service was personalised around their needs</p> <ul style="list-style-type: none"> • <i>"The recovery program is catered for my needs"</i> • <i>"It has been very collaborative, not prescribed, very individualized"</i> • <i>"He [staff from multidisciplinary team] tailored his advice to my situation and answered all my questions with thought"</i> 	3 (1.7%)	0 (0%)	0 (0%)

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) and the % of total group responders are reported in the column header.

Negative feedback pinpointed the necessity of providing quicker access to Long COVID service, with many responders reporting they had to wait for many months, potentially because either the service was not established at the time they needed it or because there were delays in the pathway to get a referral to and/or access the service. Because of these issues, some responders had to access rehabilitation services via alternative means such as private care. Some responders found the rehabilitation they had received was too generic and did not consider their specific clinical needs. Some service users were worried about what would happen once they are discharged from the Long COVID service. A small number of responders did not find the service useful to help them in their recovery.

Themes (Negative feedback – specific for the Long COVID service)	Existing service users N = 177 (79.4%)	Follow-up N = 25 (78.1%)	Discharge N = 37 (94.9%)
Referral/access to the Long COVID service is too slow <ul style="list-style-type: none"> “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 (13%)	2 (8%)	5 (13.5%)
Those with Long COVID needed to find support independently <ul style="list-style-type: none"> “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 (5.1%)	0 (0%)	1 (2.7%)
The advice/treatment offered is too generic and not enough tailored around individual needs <ul style="list-style-type: none"> “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 	11 (6.2%)	2 (8%)	2 (5.4%)

<p><i>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"</i></p> <ul style="list-style-type: none"> <i>"Staff knowledgeable and teaching excellent but too much emphasis on exercise which is not appropriate for many with Long COVID"</i> <i>"Maybe a one on one session for individual needs may have enhanced experience"</i> 			
<p>Uncertain support after Long COVID service discharge</p> <ul style="list-style-type: none"> <i>"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"</i> <i>"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?"</i> <i>"What happens going forward after being discharged from rehabilitation?"</i> 	3 (1.7%)	0 (0%)	1 (2.7%)
<p>Long COVID service was not helpful</p> <ul style="list-style-type: none"> <i>"No caused more anxiety and stress"</i> <i>"The Long COVID service is not fit for purpose. Poor practitioners with no knowledge or care for Long COVID sufferers"</i> <i>"No improvements with clinic"</i> 	3 (1.7%)	0 (0%)	1 (2.7%)

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) and the % of total group responders are reported in the column header. Each responder might have contributed to more than one theme.

A number of general negative themes were extracted. These were not specific to the Long COVID service, but are reported since they provide further context on the overall experiences of those who have received Long COVID rehabilitation. Some responders highlighted issues when interacting with general practitioners (GPs), since some GPs appeared to be unprepared in dealing with Long COVID and often were not aware of how to refer individuals in need to the Long COVID service. Some responders felt they were forgotten by the healthcare system, especially in the first months after the pandemic started and when Long COVID was still not well recognised as a medical condition by the healthcare community. Others highlighted how their Long COVID symptoms were not accepted by the rest of the social/healthcare community and they felt 'invisible'. Many asked for more support in explaining to their employers about the effects of Long COVID so they can get more assistance. The responses also revealed a sense of fear and being overwhelmed by a condition that is still not well understood.

Themes (Negative feedback – not specific for the Long COVID service)	Existing service users N = 177 (79.4%)	Follow-up N = 25 (78.1%)	Discharge N = 37 (94.9%)
GP staff not educated enough on Long COVID, not aware of the Long COVID service and/or not supportive <ul style="list-style-type: none"> “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 (14.7%)	2 (8%)	4 (10.8%)
Responders feel forgotten <ul style="list-style-type: none"> “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 (8.5%)	2 (8%)	5 (13.5%)
Responders feel invisible and that their Long COVID issues are not believed <ul style="list-style-type: none"> “Lots of the symptoms aren’t visible and so it can be difficult to get support from family and work” 	5 (2.8%)	0 (0%)	0 (0%)

<ul style="list-style-type: none"> • <i>"Left alone to deal with effects of COVID there were interminable long periods when you felt invisible"</i> • <i>"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"</i> 			
Responders need more support in dealing with employers <ul style="list-style-type: none"> • <i>"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"</i> • <i>"More employment support, particularly for healthcare staff due to pressure for us to go back into work"</i> • <i>"A better understanding of COVID should be given to employers"</i> • <i>"[Tell me] what financial support I could have due to being off work for a substantial length of time"</i> • <i>"Help get longer time off as we can't live like this trying to work and survive"</i> 	7 (4%)	0 (0%)	1 (2.7%)
Responders feel scared and overwhelmed about their conditions, uncertain about their future <ul style="list-style-type: none"> • <i>"Without wanting to be dramatic Long COVID is life changing for me"</i> • <i>"My experience has been life changing, I wish we could erase the last 18 months of COVID so I can get back to normal, whatever normal will be"</i> • <i>"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> • <i>"I've never felt so ill and alone, it's been over a year for me"</i> 	13 (7.3%)	0 (0%)	0 (0%)

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) and the % of total group responders are reported in the column header. Each responder might have contributed to more than one theme.

The survey also collected suggestions to further improve the Long COVID service (some of these have already been implemented in some of the LHBs). These included the preference for some service users to have face-to-face support, the need to increase the frequency of the appointments, the opportunity to interact with some others Long COVID sufferers in group sessions, and the option of receiving more electronic communications. It was also suggested to simplify the referral process, to keep monitoring service users and update them on new treatments in the months ahead and to 'publicise' the Long COVID service more.

Themes (Suggestions for improvement)	Existing service users N = 177 (79.4%)	Follow-up N = 25 (78.1%)	Discharge N = 37 (94.9%)
Responders prefer face-to-face support <ul style="list-style-type: none"> "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 (6.8%)	6 (24%)	6 (16.2%)
Increase the frequency of appointments <ul style="list-style-type: none"> "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 (2.8%)	0 (0%)	0 (0%)
Responders would like group therapy with others suffering with Long COVID symptoms <ul style="list-style-type: none"> "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 (1.1%)	2 (8%)	1 (2.7%)
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: <ul style="list-style-type: none"> "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" 	14 (7.9%)	2 (8%)	4 (10.8%)

<ul style="list-style-type: none"> • <i>"Possibly a review after another period of time - say 6 months- to see if things have changed or understanding of COVID has changed"</i> <p>Some responders recommended making referral easier</p> <ul style="list-style-type: none"> • <i>"It would be better if they could make onwards referrals instead of having to go back through to the GP"</i> • <i>"More continuity between services and easier referrals"</i> <p>Some responders would prefer more electronic communication:</p> <ul style="list-style-type: none"> • <i>"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"</i> • <i>"Allowing people (especially with disabilities such as autism) to communicate via email to make it more accessible"</i> • <i>"Electronic appointments (text/email) would be better"</i> • <i>"communication- sending of information electronically"</i> <p>Some responders reported services for people with Long COVID are not known well enough:</p> <ul style="list-style-type: none"> • <i>"Contact details were poor, needed to chase up. Switchboard didn't recognise the service"</i> • <i>"Feels more publicity is needed"</i> • <i>"Some people still not aware of COVID team"</i> <p>Other suggestions:</p> <ul style="list-style-type: none"> • <i>"Explain things in 'layman' terms"</i> • <i>"Admin could improve, letters have been received after appointment"</i> • <i>"More support on managing fatigue and cognitive issues"</i> • <i>"More consultant-led Long COVID clinics in all HB's covering all specialty's cardiac, respiratory and neurological"</i> 			
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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) and the % of total group responders are reported in the column header. 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: 93.8% of the 'Follow-up' group, 89.2% of the 'Discharge' group and 87.9% of the 'Existing service users' group.

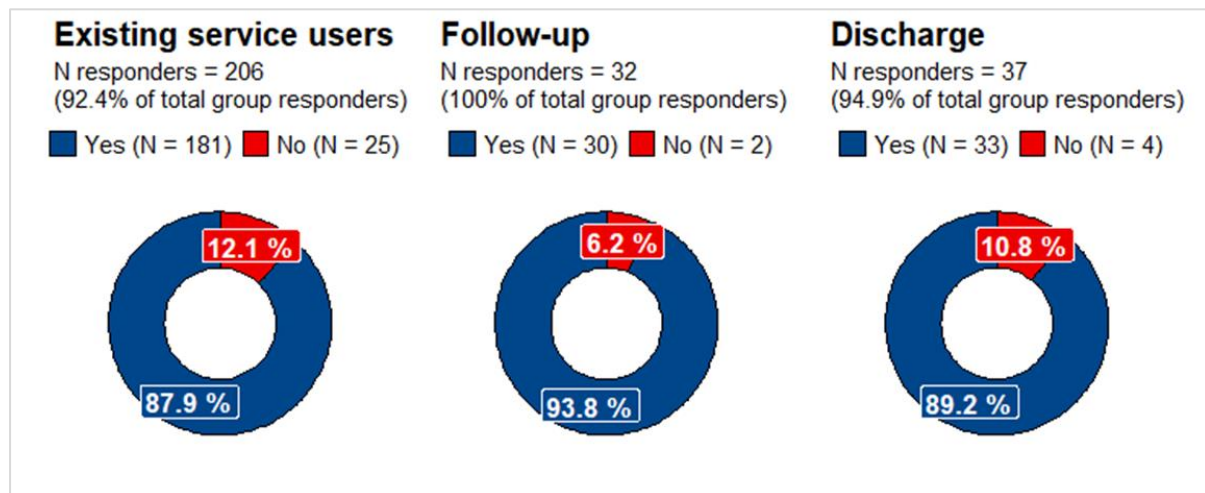


Figure 17. Donut charts for [Q21]: "Would you recommend this service?"



3.1.8 Analysis of additional responses

A total of 171 responses were excluded from the main analysis because of reasons explained in Section 2.1.4. This section includes the analysis of their answers.

Starting with their demographics (Table 18, Figure 18 and Figure 19), the majority of additional responders were females (77.8%), the most frequent age range was 41-50 (36.8%), most responders were of White ethnic background (97.1%) and the most frequent employment description was 'working full-time' (43.3%).

		Additional responders
Total sample size		171 (100%)
Gender	Female	133 (77.8%)
	Male	37 (21.6%)
	Non-Binary	1 (0.6%)
	Prefer not to say	0 (0%)
Age range	17 and under	1 (0.6%)
	18 - 30	2 (1.2%)
	31 - 40	25 (14.6%)
	41 - 50	63 (36.8%)
	51 - 60	60 (35.1%)
	61 - 70	19 (11.1%)
	71 - 80	1 (0.6%)
	81 - 90	0 (0%)
	91 and over	0 (0%)
Language used to respond	English	171 (100%)
	Welsh	0 (0%)

Table 18. Demographics of additional responders.

**'Additional' survey responders**

N responders = 170 (99.4% of total group responders)

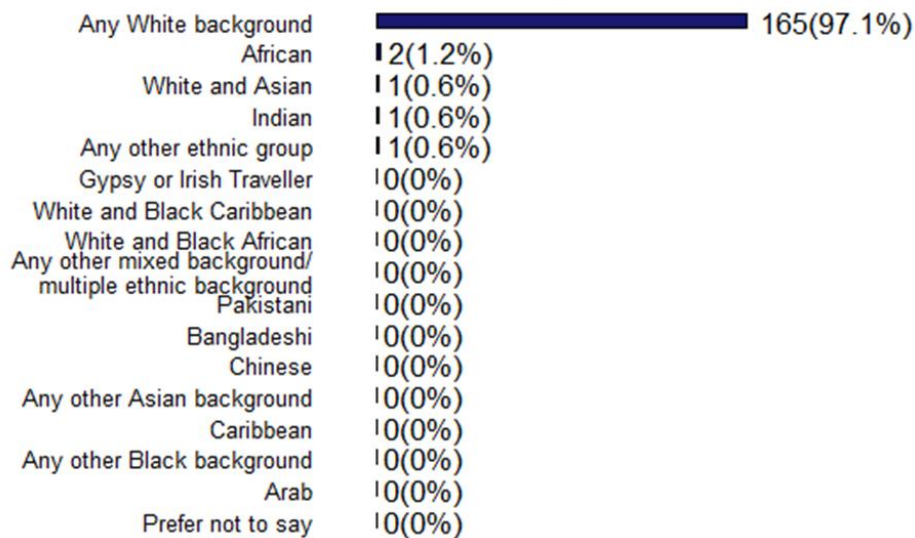


Figure 18. Bar plots for: [Q3] "Please tell us your ethnicity".

'Additional' survey responders

N responders = 171 (100% of total group responders)

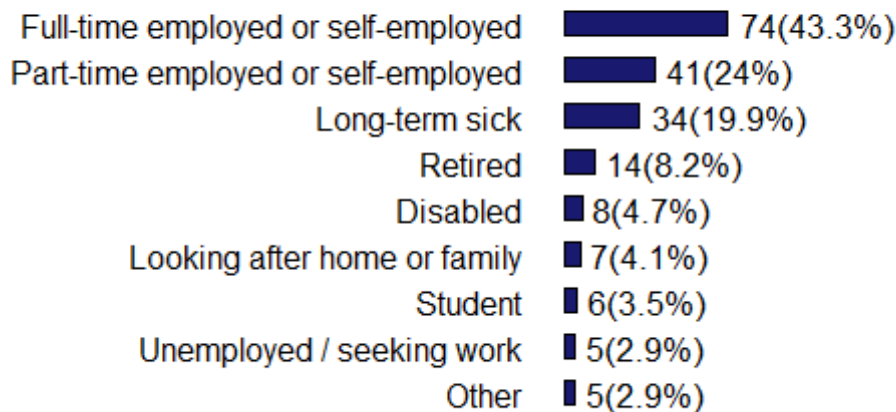


Figure 19. Bar plots for: [Q4] "Which of these definitions describe your employment status?" Multiple responses per responder were allowed for this question (i.e., for each bar, 100% would represent that all responders chose that option).

The most frequently experienced COVID-19 symptoms (>50%) by the additional responders were 'Fatigue' (88.9%), 'Brain fog' (87.7%), 'Shortness of breath' (78.4%), 'Joint pain' (68.4%), 'Headache' (61.4%), 'Insomnia' (58.5%), 'Dizziness' (55.6%), 'Chest pain/tightness' (54.4%), 'Heart palpitations' (53.2%) and 'Depression and anxiety' (50.9%).

'Additional' survey responders

N responders = 171 (100% of total group responders)

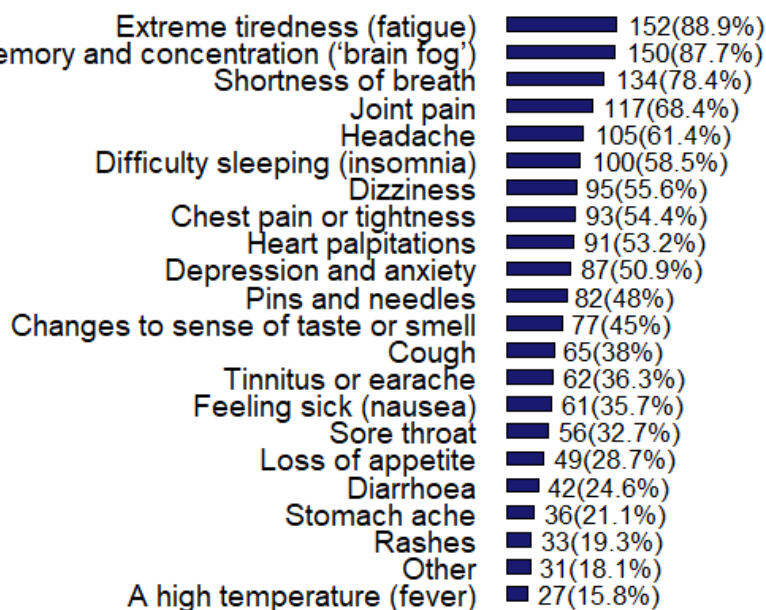


Figure 20. Bar plots for [Q6]: *"Please tell us about any symptoms you have experienced today due to COVID-19"*. Multiple responses per participant were allowed for this question (i.e., for each bar, 100% would represent that all responders within the group chose that option).



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

OTHER SYMPTOMS	'Additional' responders N = 31 (18.1%)
Pain (e.g. muscle pain/stiffness, general pain in the body, local pain to back, arm, chest, face or neck)	7 (22.6%)
Mobility issues (including leg issues, balance issues)	6 (19.4%)
Voice, mouth, throat and swallow issues	4 (12.9%)
Post-exertional malaise	3 (9.7%)
Vision and eye issues	3 (9.7%)
Cardiovascular issues (e.g. tachycardia)	2 (6.5%)
Dysautonomia issues	2 (6.5%)
Hair loss	2 (6.5%)
Numbness of body (e.g. feet, face)	2 (6.5%)
Allergy	1 (3.2%)
Vivid dreams	1 (3.2%)
Constant muscle fasciculations	1 (3.2%)
Issues with feet and hands (cold, sore)	1 (3.2%)
Flatulence	1 (3.2%)
Gastrointestinal issues	1 (3.2%)
Hearing loss	1 (3.2%)
Hypersensitivity (e.g. to light, sound, pain or skin hypersensitivity)	1 (3.2%)
Involuntary tremor	1 (3.2%)
Extreme mood swings	1 (3.2%)
Excessive sweating/feeling hot and/or inability to regulate body temperature	1 (3.2%)
Under-active thyroid	1 (3.2%)
Transient ischemic attack	1 (3.2%)

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 header

Finally, 131 'additional' responders (76.6% of total 'additional' responders) provided feedback via free text. Themes were summarised in Table 20. Responders expressed a feeling of having been forgotten by the healthcare system in general and not being well supported by their GPs. Some responders explained they were referred to the long COVID service but are still waiting (some of them after many months) for interaction. Others appear unaware of Long COVID services in Wales, with some responders reported lack of service in North Wales. Some responders felt they did not have any other choice but to look for help elsewhere, via private healthcare in Wales or using a dedicated support group on Facebook. They recommended increasing the number of Long COVID services in Wales and the creation of a 'one stop shop' clinic which would provide more equal and easier access to Long COVID diagnosis and treatment.

Themes	'Additional' responders N = 132 (77.2%)
Responders feel forgotten <ul style="list-style-type: none"> • <i>"No help for Long COVID"</i> • <i>"I have not been contacted by anyone concerning this because I caught it Jan 2020"</i> • <i>"I had mild COVID April 2020 I wasn't followed up to see how I was afterwards"</i> • <i>"Haven't had any care. Not seen anyone"</i> • <i>"I have felt totally unsupported during my very scary experience of thinking my end was near on several occasions with no medical support"</i> • <i>"Actually contact people instead of just a survey"</i> • <i>"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"</i> • <i>"More information needed as there is none"</i> • <i>"I'm still waiting for referrals and feel I'm forgotten about"</i> 	50 (37.9%)
GP staff not prepared in dealing with Long COVID, not aware of the Long COVID service and/or not supportive <ul style="list-style-type: none"> • <i>"The GP has no idea when I might hear back neither can they give any indication of the waiting time/list"</i> • <i>"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"</i> • <i>"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> • <i>"I have given up even trying to ring the GP as the effort is too much and so frustrating"</i> • <i>"Educate doctors more. I have been ill 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"</i> • <i>"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"</i> 	31 (23.5%)

<ul style="list-style-type: none"> “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” 	
<p>Referral/access to the Long COVID service is too slow</p> <ul style="list-style-type: none"> “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 (20.5%)
<p>Responders do not know how to access Long COVID support or are not aware of any service</p> <ul style="list-style-type: none"> “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 (15.6%)
<p>Lack of resources/capacity</p> <ul style="list-style-type: none"> “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 (3.8%)
<p>Lack of Long COVID clinics in North Wales</p> <ul style="list-style-type: none"> “Provide clinics in North Wales” 	4 (3%)
<p>Responders needed to find support independently</p> <ul style="list-style-type: none"> “The only rehab support I have had is via Nuffield programme which I found out about through the Long COVID Wales group” 	17 (12.9%)

<ul style="list-style-type: none"> • "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 !!!!!" 	
<p>Responders feel that a "one-stop shop" COVID clinic is needed</p> <ul style="list-style-type: none"> • "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 (6%)
<p>Other suggestions for improvement</p> <ul style="list-style-type: none"> • "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 (5.3%)

Table 20. Additional responders experience feedback extracted from 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?" Number of responders (N) and the % of total "extra" responders are reported in the column header.

3.2 Social Return of Investment (SROI) interim analysis

Both C&V UHB's and CTM UHB's Long COVID Rehabilitation Services have been running for approximately a 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 also started this provision, following user feedback.

At this stage, the 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 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 they were coping, 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. This was not only in a gradual return to work, but to feel they had something to explain to colleagues or family how gradual this had to be. 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 started to gather data from GPs and one employer as part of the wider stakeholder impact mapping, and this will be incorporated into the final SROI calculation in March 2022. Feedback from GPs is mixed, with some GPs feeling that the service had not had an impact directly on their practices. 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 an impact directly from the service. This may be related to the very long and gradual recovery process, and will be investigated in continuing work.

At this interim stage, both interventions have a social value ratio of greater than 1, meaning that for every £1 put in, there is a greater return in value to the included stakeholders, even with the relatively conservative assumptions being made. As we work to include families, GPs and other groups as stakeholders this return may be expected to increase. There is also additional work to be completed with stakeholders in verifying financial proxies and the relative importance and duration of the outcomes.

3.3 Local Health Boards data summary

3.3.1 Long COVID definitions

The definitions used by each LHB to define those who can access their Long COVID service are reported in Table 21. Most LHBs referred either to NICE (2021) or WHO (2021) definitions.

Local Health Board	Definition of Long COVID for admission to the Long COVID service
AB UHB	We use the definitions created by NICE to guide the approach of the team to meeting the needs of the patient group. We do not require a formal diagnosis of COVID to be offered services from the post-COVID teams
BC UHB	The BCUHB Long COVID service uses the WHO definition: people who continue to have COVID 19 symptoms* lasting longer than 12 weeks that cannot be explained by an alternative diagnosis. (*clinically diagnosed with symptoms of COVID-19, with or without a positive SARS-CoV-2 test (PCR, antigen or antibody))
C&V UHB	Primary, the NICE definition but we do include the WHO new definition of Post COVID Condition
CTM UHB	Post COVID-19 Syndrome is a diagnosis of exclusion: <ul style="list-style-type: none"> • by NICE definition <i>“signs and symptoms that develop during or after an infection consistent with COVID-19, continue for more than 12 weeks and are not explained by an alternative diagnosis”</i> • <i>“After ruling out acute or life-threatening complications and alternative diagnoses, consider referring people to an integrated multidisciplinary assessment service”</i>.
HD UHB	WHO definition- people* who continue to have COVID 19 symptoms lasting longer than 12 weeks/ 3 months that cannot be explained by an alternative diagnosis. (*clinically diagnosed with symptoms of COVID-19, with or without a positive SARS-CoV-2 test (PCR, antigen or antibody))
PT HB	The PTHB COVID Recovery and Rehabilitation Service uses the definition defined with the NICE Guidance (NG188). Individuals do not need to have had a positive PCR to access to service.
SB UHB	<ul style="list-style-type: none"> • NICE guidelines COVID 19 rapid guideline • Managing long term effects of COVID 19 -version Nov 11th 2021

Table 21. “Which definition of Long COVID do you use when identifying/referring individuals to your Long COVID service? (e.g. NICE, WHO, or other internal definition)”

3.3.2 General description of the 'Adferiad' (Recovery) programme

This section includes descriptions directly collected from LHBs on how they have implemented the 'Adferiad' (Recovery) programme for Long COVID, in line with what was requested by WG in their 'Reporting Template'. Some LHBs preferred not to share the information in this National Report since they are providing this description separately and wanted to avoid duplication. The responses received have been included in Table 22.

Local Health Board	'Adferiad' (Recovery) programme description
PT HB	<p>During the establishment and development of the COVID Recovery and Rehabilitation Service in Powys the team was able to utilise the skills and knowledge of the existing team to ensure that the service was based on lessons learnt from the already established post viral fatigue service.</p> <p>As a result of feedback obtained from the initial cohort of Adferiad surveys completed by individuals accessing the service it was evident that there was confusion about where the individual had been referred, to as the COVID Recovery and Rehabilitation service is integrated within the Pain and Fatigue Management Service. Hence, Powys Teaching Health Boards Pain and Fatigue Management service is being rebranded as the Powys Living Well Service to include the development of the COVID Recovery and Rehabilitation Service and the Weight Management Service.</p> <p>The funding received as part of the Adferiad Programme has allowed the Health Board to engage with an independent healthcare technology research centre (CEDAR) to provide a detailed and unbiased review and evaluation of the COVID Recovery and Rehabilitation service. It has supported the recruitment and retention of staff to provide and develop the service including an Advanced Practitioner, General Practitioner and Administrative support. The Health Board has recruited a temporary project manager to develop and deliver training across Powys to support staff in Shared Decision Making, the purchase of the EQ5QDL License for the Health Board to support PROMS collection digitally and the procurement of Musical Instruments (Recorders) to support individuals accessing the COVID Recovery and Rehabilitation Service.</p> <p>Over 95% of the contacts at present are being undertaken virtually and the Adferiad funding has been utilised to support this through the upgrade of digital equipment for staff including laptops, webcams, headsets etc and the ongoing development of an e-learning package to support the individuals in their recovery.</p> <p>In order to ensure equity of services across Powys, the service is available as face-to-face contacts in both the North and South of the county but predominantly online with the assistance of the services Digital Support Team who are available to assist with people accessing virtual appointments. For individuals that are resident in Powys and staff employed within PTHB regardless of where they live, they can be referred to the service via their GP and the interventions are tailored to the individual's needs.</p> <p>The Head of the Powys Living Well Service and the lead GP have recently attended Powys Teaching Health Boards Protected Learning Time sessions with GPs from across Powys. In addition, all individuals accessing the service invited to be part of the services' Experience Panel where individuals are afforded the opportunity to help shape and develop the service at a monthly meeting.</p>

Table 22. *"Please provide a general description of the 'Adferiad' programme within your health Board over the last 6 months. This should include any changes made as a result of learning, patient feedback and how funding has been utilised. You should also indicate here how you have ensured equity of provision across the population. This section should also include any relevant engagement activity undertaken"*

3.3.3 Demand for accessing Long COVID services

Table 23 shows the demand for accessing the Long COVID service in the various LHBs, providing a summary as recommended by WG in their 'Reporting Template' for the 'Adferiad' (Recovery) programme. Since different LHBs have implemented their Long COVID service in different ways, these numbers are only indicative and comparisons are not recommended. We have been acknowledged that each LHB will provide WG with more detailed information about their service's demand in a separate report.

Question	AB UHB	BC UHB*	C&V UHB	CTM UHB	HD UHB	PT HB	SB UHB
Number of those accessing the Long COVID service	61 (120 referrals)	5 (149 referrals)	571 (886 referrals**)	392 (485 referrals)	65 (124 referrals)	97	390****
% of Long COVID service users given advice/self-management	100%	100%	100%	89%***	100%	100%	100%
% of Long COVID service users referred to rehabilitation	58%	N/A	100%	79%	74%	41%	100%
% of Long COVID service users referred to secondary care outpatients	31%	N/A	7%	5% (of those who received rehab)	0%	2%	N/A
Average number of Long COVID Service appointments per person	2	N/A	3.8	6	3.7	6	14 (with MDT); 2.01 (with occupational therapist)

Table 23. Demand for accessing the Long COVID service.MDT = Multi-Disciplinary Team; N/A = Not Available.

*BC UHB opened their Long COVID service on 02/12/2021, thus they did not have enough data to answer the last 3 questions. ** Total number of processed referrals for CAVUHB were 987, however, some referrals were removed because they were duplicates or inappropriate referrals. ***This is not 100% because some patients did not attend their first appointment or there were still waiting for their assessment at the time of reporting.

**** This number includes patients referred either to the post-COVID rehabilitation service or to the occupational therapy staff wellbeing service. Over 240 patients were referred to the post COVID -19 rehabilitation programme for the period September 2020- December 31st 2021

Table 24 shows when the information was collected for Table 23.

Local Health Board	From	To
AB UHB	01/06/2021	31/12/2021
BC UHB	02/12/2021	22/12/2021
C&V UHB	04/01/2021	17/12/2021
CTM UHB	01/07/2021	31/12/2021
HD UHB	17/10/2021	31/12/2021
PT HB	01/12/2020	22/12/2021
SB UHB	01/08/2020	31/12/2021

Table 24. Collection period of service demand data from LHBs.

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5 Supplementary material

5.1 Appendix 1: National service user questionnaire

[Note: the list of symptoms was retrieved from <https://www.nhs.uk/conditions/coronavirus-covid-19/long-term-effects-of-coronavirus-long-covid/>]

5.1.1 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 (Please select one)

- ☐ 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



5.1.2 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)

- ☐ 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.

5.1.3 Section 'Your general health' (Q9-14)

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

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

MOBILITY

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

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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

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

ANXIETY / DEPRESSION

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

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

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

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

The best health
you can imagine



The worst health
you can imagine

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5.1.4 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