Independent evaluation of the needs of Long COVID service users in HIOW ICS

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DISCLAIMER

This report presents the findings of an independent evaluation of the needs of Long COVID service users in HIOW ICS. The findings and conclusions are those of the authors and do not necessarily represent the views of HIOW ICS.

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BACKGROUND

INTRODUCTION

Hampshire and Isle of Wight (HIOW) Integrated Care System (ICS) is experiencing a rise in referral rates to Allied Health Professionals (AHPs) for Long COVID service users. The ICS Strategic Long COVID Group wished to understand service users' appetite and opportunities for non-NHS support as having a non-NHS asset could provide an 'emotional buffer' to Long COVID sufferers in the absence of immediate access to scheduled care. This was to address the ICS's concern that AHPs may become overwhelmed by service users with a high degree of psychological overlay on physical symptoms, and that service provision at an organisational level may become unsustainable.

Wessex Academic Health Science Network Insight team (WAHSN) was approached to undertake a rapid evaluation of the needs of Long COVID sufferers. This involved a series of interviews and focus groups with adults living with Long COVID, supplemented by a short survey administered online via the Long COVID operational lead to all service users on the ICS Long COVID caseload. WAHSN collected service users' views between September 2021 and November 2021. This report is intended to support commissioning decisions by the ICS Strategic Long COVID Group going forward.

THE HIOW ICS LONG COVID SERVICE

During the period of this evaluation (September to November 2021), the HIOW ICS Long COVID service reported a caseload of approximately 1000 service users spread across three different providers (Southern Health NHS Foundation Trust, Solent NHS Trust, and Isle of Wight [IOW] NHS Trust) and six Integrated Care Partnerships (ICP). Approximately 577 service users are supported by Southern Health NHS FT (North and Mid Hampshire ICP, West Hampshire ICP and South and East Hampshire ICP), approximately 304 service users are supported by Solent NHS Trust (Southampton ICP and Portsmouth ICP), and approximately 124 service users are supported by the IOW NHS Trust.

The approximate numbers of staff by whole time equivalent (WTE) from April 2021 to September 2021 for each ICP are included in Table 1 below. The overall workforce has increased with the enhanced service provision over that period, as shown in Table 1. All ICPs initially recruited the Band 8a (aside from IOW, who have no Band 8a staff), subsequently recruiting Band 7 and Band 6 staff members. Recruitment to the posts created as part of the enhanced service provision was complete in October 2021. These data are estimates only as staffing has been shifting due to change in NHS Plan and supported funding.

A key deliverable of the Long COVID service is a clinician assessment. All the services offer telephone, virtual or face- to-face assessments depending on clinical need, as well as onboarding to the 'Living with Covid' App. The App has the functionality to message the clinicians directly and includes rehabilitation programmes, diary trackers, and resources.

Table 1. Workforce according to each ICP by WTE, pay band and profession

ICP	WTE of the staff delivering the service (April to September)	Pay band of the staff delivering the service	Professional Background of staff delivering the service
North and Mid Hampshire	0.9 to 1.5	All	Physiotherapist(s)
	0.4	8a	
	0.6	7	
	0.5	6	
West Hampshire	0.6 to 1.5	All	Occupational Therapist(s), Physiotherapist(s)
	0.4	8a	
	0.6	7	
	0.5	6	
South and East Hampshire	0.4 to 1	All	Physiotherapist(s)
	0.4	8a	
	0.6	7	
Southampton	0.4 to 1	All	Occupational Therapist(s), Physiotherapist(s)
	0.4	8a	
	0.6	7	
Portsmouth	0.4 to 1	All	Occupational Therapist(s), Physiotherapist(s)
	0.4	8a	
	0.6	7	
Isle of Wight	0.6 to 0.8	7	Physiotherapist, Advanced Nurse Practitioner

EVALUATION QUESTION AND OVERVIEW OF METHODS

A multi-method approach was undertaken. This included two components: 1) a Long COVID service wide survey for all service users referred to the Long COVID service (those awaiting to be assessed and those who had been assessed), with questions regarding the characteristics of the respondents, as well as free text questions (see Appendix 1); and 2) online (via MS teams or Zoom Pro) or telephone qualitative interviews and focus groups with service users of the Long COVID service who had been assessed.

These methods were used to answer the evaluation question: **"What non-NHS support may help Long COVID service users adjust to their new circumstances and self-manage their condition?".**

The separate findings sections provide detail on the sampling criteria, recruitment strategies and data analysis processes for the respective components of this evaluation.

This convergent evaluation used a segregated method of analysis, with the survey and interview or focus group data initially analysed separately[1, 2]. The findings were then integrated using methods of triangulation at synthesis meetings with all the evaluators present[2]. The synthesised findings section presents the results from the synthesis meetings, describing the comparison of data between the survey and interviews or focus groups. The synthesis meetings explored whether the survey and interview or focus group data confirmed, refuted, or complemented each other[3]. In the instances where the data was not present in both data sets, it was classified as 'silent'[3].

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[1] Creswell, J.W. and Clark, V.L.P., 2017. Designing and conducting mixed methods research. Sage publications.

[2] Sandelowski, M., Voils, C.I. and Barroso, J., 2006. Defining and designing mixed research synthesis studies. Research in the schools: a nationally refereed journal sponsored by the Mid-South Educational Research Association and the University of Alabama, 13(1), p.29.

[3] Heyvaert, M., Maes, B. and Onghena, P., 2013. Mixed methods research synthesis: definition, framework, and potential. Quality & Quantity, 47(2), pp.659-676.

FINDINGS 1 - LONG COVID SERVICE WIDE SURVEY

Key points

1. At present, a reasonably large number of service users on the Long COVID caseload are either not empowered to identify support or it is not currently detectable or available. A publicly visible Long COVID service has yet to be established. Of the 139 respondents, 22.3% did not offer any feedback on support they personally sought or actually used. Furthermore, of the 108 respondents who fed back, 20.4% explicitly stated they had not sought any non-NHS support for Long COVID. In addition, with the benefit of hindsight, only 76 (54.7%) of the 139 respondents had a view of what support they would like in the future.
2. Just over half of service users sought support from family, friends, or work colleagues. A quarter sought digital or online self-help support, a fifth sought non-digital or online support, e.g., exercise, yoga. Some service users (16.7%) reported the Living with COVID App as a source of support and some (13%) sought private healthcare solutions.
3. With the benefit of hindsight, 30.3% described the need for support groups in a variety of forms: clinician-led and peer-led, and both face-to-face and online.
4. Due to the long waits (83% waiting 3 months or more) to be assessed by the Long COVID service, more information and/or discussion with clinicians was desired, in the gap between referral and assessment, to generally inform and support current symptoms.

The survey was sent to all eligible service users on the HIOW ICS Long COVID caseload (1005 at the start of the survey) and open for one month. In total, 139 survey responses were obtained during October 2021, representing a 14% overall response rate. Most survey responses were from service users within Portsmouth ICP and IOW ICP. Response rates by provider were: 44% for IOW NHS Trust, 27% for Solent NHS Trust and 0.5% for Southern Health NHSFT. No survey responses were received from the North and Mid Hampshire ICP and West Hampshire ICP. The overall response rate is reasonable for this type of service-wide online survey, however, the response rates for two ICPs were good and thus the findings are largely relevant to Portsmouth ICP and IOW ICP.

Table 2 describes the 139 survey respondents as predominately female, White British, and employed full-time. People of different ages completed the survey, but the majority were aged between 51-60 years old. About half of the survey respondents had been assessed by the Long COVID service. For those waiting to be assessed, a third have been waiting over six months and many (83.1%) at least three months.

> *"The phone calls are not that helpful to be honest. The suggestions, while well meaning, have not really unpicked or supported the issues I have been left with as a result of COVID. I am still awaiting a response from the fatigue clinic – it's been 7 months since my initial long covid referral." (Survey ID 85)*
>
> *"My mental health has suffered due to the long wait getting help for finance support, pain support etc." (Survey ID 100)*

Table 2. Survey respondent demographics

Demographic factor	Response option	Number and %
Gender	Female	**93 (66.9%)**
	Male	46 (33.1%)
Age	18-30	11 (7.9%)
	31-40	15 (10.8%)
	41-50	34 (24.5%)
	51-60	**48 (34.5%)**
	61-70	27 (19.4%)
	71-80	4 (2.9%)
Ethnicity (self-described)	White British or White English	**124 (93.9%)**
	European, unknown ethnicity	3 (2.3%)
	European White	1 (0.8%)
	Asian	1 (0.8%)
	Welsh White	1 (0.8%)
	African	1 (0.8%)
	Mixed other	1 (0.8%)
Employment status (self-described)	Employed full-time	**50 (37.3%)**
	Employed but unable to work due to Long COVID	26 (11.9%)
	Retired	19 (14.2%)
	Employed part-time	16 (11.9%)
	Unemployed	11 (8.2%)
	Self employed	5 (3.7%)
	Student	5 (3.7%)
	Employed but on reduced hours due to Long COVID	2 (1.5%)
Location	Portsmouth (Solent NHS Trust)	**57 (41.0%)**
	IOW (IOW NHS Trust)	54 (38.8%)
	Southampton (Solent NHS Trust)	25 (18.0%)
	South and East Hampshire (Southern Health NHSFT)	3 (2.2%)
Assessed by Long COVID service	Yes	**70 (50.7%)**
	Waiting to be assessed	66 (47.8%)
	Not sure	2 (1.4%)
Length of time waiting to be assessed	More than 6 months	**23 (35.4%)**
	4-5 months	16 (24.6%)
	3-4 months	15 (23.1%)
	1-2 months	7 (10.8%)
	Up to 1 month	4 (6.2%)

In total, survey respondents self-reported 379 instances of Long COVID symptoms, of which 31 were different symptoms (see Table 3). The predominant symptoms were fatigue and breathlessness. There were no significant differences in the predominant symptoms between ICPs, however, the number of symptoms differed. Portsmouth respondents reported 18 different symptoms, whereas IOW reported eight, Southampton reported six, and in South and East Hampshire only fatigue was reported (only three respondents from this ICP). There were no differences in the predominant symptoms between gender or age groups.

Table 3. Self-reported symptoms of Long COVID from 139 service users

Self-reported symptom	Number	% of total instances (n=379)
Fatigue	114	30.0
Breathlessness	74	20.0
Brain fog	32	8.4
Joint pain	20	5.2
Headaches	18	4.7
Memory loss	15	3.9
Loss of smell and taste	12	3.1
Heart Palpitations	12	3.1
Muscle weakness	11	2.9
Sleep disturbance	9	2.4
Chest pain	8	2.1
Depression	7	1.8
Dizziness	7	1.8
General pain	6	1.6
Sensitive skin	6	1.6
Anxiety	5	1.3
Coughing	3	0.8
Nausea	3	0.8
Sore throat	2	0.5
Tinnitus	2	0.5
Low immune system	2	0.5
Hoarse voice	2	0.5
Loss of appetite	1	0.3
Loss of hair	1	0.3
Migraine	1	0.3
Diarrhoea	1	0.3
Vision problems	1	0.3
Vertigo	1	0.3
Fever	1	0.3
Fluctuating Blood Pressure	1	0.3
Irritable	1	0.3

Of 371 reported instances of Long COVID symptoms across all respondents who also reported their employment status, 251 (67.7%) were linked to people who were employed and 120 (32.3%) were linked to people who were not employed or retired.

Of 111 reported instances of the symptom fatigue, 78 (70.3%) were linked to people who were employed and 33 (29.7%) were linked to people who were not employed or retired.

> *"I lost my stamina, endurance and wellbeing. Along with the numerous other symptoms which grind me down, remaining positive about my current situation and the future is very difficult. My health and my social situation has collapsed. I take one day at a time now. (Survey ID 54)*

Similarly, of 72 reported instances of the symptom breathlessness, 45 (62.5%) were linked to people who were employed and 27 (37.5%) were linked to people who were not employed or retired.

People who were employed reported more symptoms and the findings suggest being employed may increase or exacerbate the prevalence of fatigue and breathlessness.

Service users were asked if they felt disadvantaged in getting access to Long COVID support due to any personal demographic reasons. Overall, 67 responses were obtained on this question and 55 (82.1%) reported they did not feel disadvantaged and 12 (17.9%) reported they did. Four (6%) respondents felt disadvantaged due to their age – by being perceived as young and fit and not requiring support or due to 'these symptoms are what happens when you get older' statements by their clinician. Three (4.5%) felt disadvantaged by clinician decisions not to support, two (3%) gave no reason, and single responses were reported for these reasons – disadvantaged due to being a single parent (1.5%), due to geographic isolation (1.5%), and poor digital ability to self-help (1.5%).

NON-NHS SUPPORT SOUGHT, RECEIVED OR USED

A key question in the survey was: "Whilst you've been waiting for formal NHS services to support your symptoms/impact of Long COVID, please tell us what non-NHS support you have sought/received/used (e.g., from voluntary organisations, social organisations, from family/friends)."

Of the 139 survey participants, 108 (77.7%) answered this key question and 31 (22.3%) did not.

It is assumed that a fifth of survey respondents did not seek nor receive any form of non-NHS support. Related to this, of the 108 respondents who answered the question, 20.4% (see Table 4) explicitly reported they had not sought any non-NHS support for Long COVID. This would suggest a reasonably large number of service users on the Long COVID caseload are either not empowered to identify support or it is not currently detectable or available.

Of the 108 respondents who answered the question, half reported family, friends, and work colleagues as key to Long COVID support. Support with daily activities, finances, and emotional support were the most common form of support from family, friends, and work colleagues.

Table 4. Types of support sought / received / used

Types of support sought / received / used	**Instances each support type was recorded (n=168)**	**% of total number of instances**	**% of total number of respondents to this question (n=108)***
Family / friends / work colleagues	57	33.9	52.8
Digital/online self-help activities	28	16.7	25.9
None sought independently	22	13.1	20.4
Non-digital/online self-help activities	20	11.9	18.5
Formal NHS healthcare services (inc. Living with Covid app)	18	10.7	16.7
Formal private healthcare	14	8.3	13.0
HR services	6	3.6	5.6
Voluntary sector support	3	1.8	2.8

**Does not sum to 100% due to multiple response options by respondents.*

Table 9, later in the report, describes the wide range of support sought or used, and collates this alongside the support services received, felt to be essential, and felt to be desired from the interviews and focus groups. This table has the potential to be the basis for a repository of information for clinicians to signpost to during the Long COVID assessment process and/or during ongoing support.

To enhance the survey data, the types of support sought / used are elaborated below:

> *“I have read anything/everything about Long Covid to inform myself and help myself at home through it.” (Survey ID 13)*
>
> *“I underwent 6 sessions with private acupuncture treatment. This helped my anxiety a great deal and calmed me in dealing with symptoms.” (Survey ID 22)*
>
> *“Rest and pace strategies on how to live with limited energy, manage the chronic fatigue and exercise intolerance. They have been the most helpful so far and I learned about them from other patients and healthcare professionals presenting for our support groups. During my contacts with NHS physiotherapists and medics, it transpired that they are very much unaware of these strategies are adamant to manage chronic fatigue as a deconditioning - with graded exercise therapy, which is counterproductive.” (Survey ID 113)*
>
> *“The Facebook support groups for Long COVID and ‘AbSent’ for loss of smell and taste has been a godsend.” (Survey ID 17)*
>
> *“I feel that it is important for patients to feel supported, to realise that it is affecting a lot of other people and we are not alone. The effects of the symptoms and impact on your life with long covid, effects your whole life and mental wellbeing. It can affect marriages / partnerships / family relationships, you may no longer be able to work (causes frustrations), you may no longer be able to manage everyday tasks (again frustration), heighten symptoms of any other illnesses or conditions that you may already suffer with, loneliness, isolation, lack of understanding. It would be good to have organisations that would be able to help and support not only the patient but maybe the whole family with all of these things and more because needs will be different for everyone, as we are not the same.” (Survey ID 83)*

NON-NHS SUPPORT WANTED

A key question in the survey was: “Whilst you’ve been waiting for formal NHS services to support your symptoms/impact of Long COVID, please tell us what non-NHS support you would like (e.g., from voluntary organisations, social organisations, from family/friends).”

Of the 139 survey participants, 76 (54.7%) answered this key question and 63 (45.3%) did not.

It is assumed that just under half of survey respondents did not have an opinion on support wanted, were not aware of what could help, or were disempowered to self-manage. This would suggest many service users, predominantly from the IOW and Portsmouth due to the distribution of survey respondents, on the Long COVID caseload require assistance or empowering to self-manage and navigate NHS and non-NHS support services for Long COVID.

Of the 76 respondents who answered the question (see Table 5), 30.3% described the need for support groups in a variety of forms: clinician-led and peer-led, and both face-to-face and online. These were commonly described as a place to share experiences, reduce anxiety, offer advice, and learn more about available support.

> *“A local self-help support group would be helpful to people with Long COVID, to discuss experiences, strategies for recovery, source material etc.” (Survey ID 10)*

A young person's support group was also requested by one survey respondent.

More information and/or discussion with clinicians was desired, to generally inform and support current symptoms, particularly due to the long waits most experienced to be assessed by the Long COVID service. Furthermore, there was a desire for a crisis helpline for when symptoms were overwhelming.

> *"I feel that as there seems to be a lengthy wait to be assessed by the Long COVID service, that maybe each GP or service that refers you to the clinic could be given a list of support/services that are available in your area, for the patient can reach out to if they would like to whilst waiting for the NHS service." (Survey ID 83)*
>
> *"I would like to have received information for a helpline or support group whilst awaiting appointment for Long COVID Clinic." (Survey ID 144)*
>
> *"I do feel that perhaps more frequent blood tests should be carried out due to the feelings that you experience in your body in case anything else is changing from the COVID and if the fatigue could be down to your B12 going down or lack of iron. I have looked at taking these tests privately but unfortunately everything seems to be expensive for these tests." (Survey ID 26)*
>
> *"Maybe someone to talk to when things get overwhelming, information pages on how to cope while things are bad" (Survey ID 4)*

Table 5. Sources of support wanted with hindsight

Type of support wanted	**Instances (from 139 respondents)**	**% of instances**	**Adjusted instances (from 76 respondents)**	**Adjusted %**
None reported	63	45.3	-	-
Need for support groups (in various forms)	23	16.5	23	30.3
Need for more information and/or discussion with clinicians	18	12.9	18	23.7
Need for more therapy options and symptom control	10	7.2	10	13.2
More support from family and/or friends	6	4.3	6	7.9
Need for more support with activities of daily living	6	4.3	6	7.9
Long COVID crisis support	4	2.9	4	5.3
Support on financial and occupational issues	3	2.2	3	3.9
More support from the Voluntary Sector	3	2.2	3	3.9
A holistic approach by NHS services	3	2.2	3	3.9
Totals	139	100	76	100

There were no differences in support wanted across the different ICPs, between age groups, ethnicity, employment status, symptoms of Long COVID, or whether as assessment had taken place or not. This would suggest the profile of support wanted, as described in this section, would be suitable to many.

One interesting difference was identified. Of the 23 service users who requested support groups (in various forms), 19 (82.6%) were female and only 4 (17.4%) were male. Whilst generally more females completed the survey, the gap between genders appears large on this particular issue. It would suggest this form of support may not be the preference of, or appropriate for, male Long COVID service users.

FINDINGS 2 – INTERVIEWS AND FOCUS GROUPS

Key points

1. Services users reported a preference towards face-to-face contact with healthcare professionals where possible, which was regular, structured, and expeditious, via a centralised, specialist Long COVID hub.
2. Service users felt the time between referral to and subsequent assessment by the Long COVID service could be better used by providing information and resources as well as offering peer support at this point in the care pathway.
3. The impact of anxiety, guilt, and grief (and the complexities these psychological symptoms overlaid on the physical symptoms) were highlighted, with the ‘unknown’ nature of Long COVID potentially precipitating their development.
4. The perceived need to seek private healthcare and/or self-fund access to support was evident due to perceived lack of support provided by NHS services.
5. Consideration of service user preferences towards models for delivery of support and the specific types of support reportedly required should be considered by commissioners to facilitate the delivery of more holistic, comprehensive assessments and individually tailored management plans.

Adults aged 18 and over, suspected or diagnosed Long COVID (12 weeks of symptoms) who had been referred to the Long COVID service and received a Long COVID service initial assessment were invited via email to attend either a focus group or an interview. Unlike the whole service survey, service users who had not been assessed were not invited to attend a focus group or interview – it was assumed they would have less to reflect upon for the purposes of this evaluation. The interviews and focus groups were audio recorded and analysed by two evaluators. To supplement the audio recordings, field notes and contextual and supporting documents were used during the thematic analysis process to ensure reflexivity from the evaluators.

Three focus groups and 17 interviews were conducted. In total, 11 service users participated in three focus groups (North and Mid Hampshire focus group: n=2; IOW focus group: n=5; Portsmouth focus group: n=4). Of the 17 interview participants, six were from North and Mid Hampshire, six were from IOW, four were from Portsmouth and one was from South and East Hampshire. Tables 6 and 7 includes a description of the participant characteristics for those in the focus groups and interviews, as a whole group and according to the ICP they’re geographically linked to.

The participants were predominately female, White British, and employed full-time or retired prior to living with Long COVID. The mean age of those in the focus groups and interviews respectively was 50 and 56 respectively and were in the sixth decile of deprivation (lowest decile of one represents the most deprived, with the highest decile of 10 representing the least deprived).

Table 6. Focus group participants characteristics

Characteristic	Whole group (n=11)	North and Mid Hampshire* (n=2)	Isle of Wight (n=5)	Portsmouth (n=4)
Gender (female)	9 (81)	2 (100)	4 (80)	3 (75)
Age (years)	50	42, 47	57	46
Ethnicity (White British or European)	11 (100)	2 (100)	5 (100)	4 (100)
Index of multiple deprivation	6	8, 8	5	7
Employment status pre-Long COVID (Working full time; Working part time; Retired; Student)	4 (36); 4 (36); 2(18); 1 (9)	0 (0); 2 (100); 0 (0); 0 (0)	2 (40); 1 (20); 2 (40); 0 (%)	2 (50); 1 (25); 0 (0); 1 (25)
Employment status post-Long COVID (Working full time; Working part time; Employed but unable to work; unemployed; Retired; Student)	1 (9); 1 (9); 5 (45); 1 (9); 2 (18); 1 (9)	0 (0); 0 (0); 1 (50); 1 (50); 0 (0); 0 (0)	0 (0); 1 (20); 2 (40); 2 (40); 0 (0); 0 (0)	1 (25); 0 (0); 2 (50); 0 (0); 0 (0); 0 (0); 1 (25)

Data reported as n (% of total n for group) except age and index of multiple deprivation, which is reported as mean.

**= actual values reported as n=2.*

Table 7. Interview participants characteristics

Characteristic	Whole group (n=17)	North and Mid Hampshire (n=5)	Isle of Wight (n=7)	Portsmouth (n=4)	South and East Hampshire* (n=1)
Gender (female)	13 (76)	5 (100)	7 (100)	1 (25)	0 (0)
Age (years)	56	53	64	46	47
Ethnicity (White British; Filipino; Unknown)	15 (94); 1 (6); 0 (0)	5 (100); 0 (0); 0 (0)	6 (86); 0 (0); 1 (14)	4 (100); 0 (0); 0 (0)	0 (0); 1 (100); 0 (0)
Index of multiple deprivation	6	8	5	3	NC
Employment status pre-Long COVID (Working full time; Working part time; Retired; Unknown)	6 (35); 4 (24); 6 (35); 1 (6)	2 (40); 2 (40); 1 (20); 0 (0)	1 (%); 2 (%); 3 (%); 1 (%)	2 (50); 0 (0); 2 (50); 0 (0)	1 (100); 0 (0); 0 (0); 0 (0)
Employment status post-Long COVID (Working full time; Working part time; Employed but unable to work; Unemployed; Retired; Unknown)	3 (18); 3 (18); 1 (6); 1 (6); 7 (41); 2 (11)	1 (20); 2 (40); 0 (0); 0 (0); 2 (40)	0 (0); 1 (14); 0 (0); 1 (14); 3 (43); 2 (29)	1 (25); 0 (0); 1 (25); 0 (0); 2 (50); 0 (0)	1 (100); 0 (0); 0 (0); 0 (0); 0 (0); 0 (0)

Data reported as n (% of total n for group) except age and index of multiple deprivation, which is reported as mean.

**= actual value reported as n=1.*

Abbreviations: NC = Not collected

CLINICAL JOURNEYS, CO-MORBID CONDITIONS AND ICPS REPRESENTED

Multiple clinical pathways were represented by the participants who took part in the interviews and focus groups. Participants included service users hospitalised when initially having symptoms of COVID-19. This included admission to A&E alone, inpatient admission but not requiring ventilatory support, inpatient admission requiring non-invasive ventilatory support and inpatient admission requiring invasive ventilatory support. Participants also included service users who required community-based support only from general practice and those who did not require any medical or healthcare professional review when initially having symptoms of COVID-19. Although not specifically asked about, 14 (50%) participants reported they had tested positive for COVID-19 and 12 (43%) reported they had received a COVID-19 diagnosis by symptoms only. It is unknown whether 2 (7%) participants tested positive for COVID-19 or received a diagnosis by symptoms only.

On average, participants had been living with Long COVID for 13 months. The three most common symptoms reported were fatigue, muscular and joint 'aches and pains', and anxiety (see Table 8). Other reported symptoms were brain fog, concentration and memory issues, breathlessness, chest tightness, palpitations, and insomnia.

Table 8. Self-reported symptoms of Long COVID from focus group and interview participants

Self-reported symptom	**Number**	**% of total instances (n=75)**
Fatigue	19	25
Breathlessness	12	17
Muscle and joint aches and pains	10	13
Chest pain	8	11
Brain fog	6	9
Anxiety	4	6
Insomnia	3	4
Autonomic nervous system dysfunction	2	3
Dizziness	2	3
Sight loss	2	3
Memory and concentration problems	2	3
Headaches	1	1
Itching	1	1
Cough	1	1
New allergies	1	1
Hoarse voice	1	1
Vertigo	1	1

Despite not being specifically asked about, 8 (45%) participants reported underlying co-morbid conditions. Other participants reported no previous co-morbid conditions prior to contracting COVID-19. The median (min, max) medications taken was 10 (0, 20).

As indicated in Tables 6 and 7 above, no service users chose to participate in focus groups in South and East Hampshire, Southampton, or West Hampshire ICPs. Also, no service users from

Southampton or West Hampshire ICPs chose to participate in interviews, and there was also only one service user interviewed in South and East Hampshire ICP.

THEMES AND SUB-THEMES

There were seven themes identified from the interviews and focus groups. These themes are stated below according to extent they were discussed. However, it is important to note this does not reduce the salience of the themes reported lower in the order.

The themes were:

1. Preferences for delivery of support
    a) Human and face-to-face contact with healthcare professionals
    b) Regular, structured, and expeditious contact with healthcare professionals
    c) Model for delivering support
2. Preferences for informational support
    a) Types of Long COVID service informational support and resources
    b) Type of peer-to-peer informational support and resources
3. Impact and exacerbation of anxiety, guilt, and grief
    a) Role of service user anxiety, guilt, and grief
    b) Unwillingness to treat Long COVID and fear of the ‘unknown’
4. Impact of co-morbid conditions on access to support
    a) Positive impact
    b) Detrimental impact
5. Peer support
6. Impact of private healthcare and self-funding on access to support
7. Empowerment and positivity to independently seek support

PREFERENCES FOR DELIVERY OF SUPPORT

Participants expressed preferences for the types of contact with healthcare professionals delivering support services and their preferences regarding timing for delivery of support services, and the model for how services could be delivered.

A) HUMAN AND FACE-TO-FACE CONTACT WITH HEALTHCARE PROFESSIONALS

The majority of participants expressed a preference for human and face-to-face contact over virtual- (video or telephone), app-, web-, or paper- (physical leaflets or booklets) based support. The majority of participants also acknowledged that this face-to-face support does however benefit from being supplemented by other formats of providing support, such as virtual- (video or telephone), app-, web-, or paper- (leaflets or booklets) based support, particularly in the instances where accessibility to face-to-face support is challenging.

> *“For me, I do drive, and I’ve got my blue badge, […], if someone is not as lucky and doesn’t drive, the bus service over here [on IOW] isn’t the greatest, how would they maybe easily get to those [face-to-face] appointments” (IV12, IOW ICP)*

As a result, some of the participants reported that a 'hybrid', tailored approach for how support was provided could be beneficial to account for the variability in fatigue and anxiety (e.g., when having a period of higher levels of fatigue or anxiety, virtual support offered to minimise need to travel to a venue) as well as transport access variability. This was felt to allow individuals to self-select their preferred methods for engaging with support services.

In addition, all the participants felt digital literacy and digital poverty could impact access to support if alternatives to virtual-, app-, or web- based were not offered.

B) REGULAR, STRUCTURED, AND EXPEDITIOUS CONTACT WITH HEALTHCARE PROFESSIONALS

Most participants reported regular, structured, and expeditious contact that was individually tailored following the onset of Long COVID symptoms was preferred given the 'unknown' nature of Long COVID symptoms would develop and how long recovery would (or in some instances, may not) take.

> *"I think that's probably the most important thing about Long COVID, everyone's experiences, although there's lots of common things, it's very individual" (FG03, North and Mid Hampshire focus group)*

A significant proportion of participants felt abandoned and had a fear of the unknown, and that they currently did not feel supported or that they had a point of contact for periodic follow-ups to 'check-in' regarding improvement or regression of their Long COVID.

> *"The important thing is that follow up, rather than being left…., the fact that it happens is the most important thing" (FG01, North and Mid Hampshire focus group)*

C) MODEL FOR DELIVERING SUPPORT

All participants reported a desire for there to be Long COVID specialists delivering the Long COVID services, which then provided a single point of contact for assessment and management. This was proposed as an alternative to the services being led by other specialties (e.g., respiratory services) who were not Long COVID experts, especially when the symptoms of Long COVID were not related to speciality running the service.

Most of the participants felt referrals should be made from one place (a Long COVID specialist service) and be followed up by the same service after being seen by the external specialist team reviewing them. This was to enable the Long COVID service to have holistic and comprehensive oversight of each service user's management. Participants felt this would than remove the onus and burden on service users who were struggling and felt stressed advocating for onward referrals and then subsequently ensuring the onward assessments occurred.

> *"I've had to chase it all up myself [neurology referral and getting management plan actioned], […], so as the patient, I've had to manage the channels of communication, […], and it's been stressful, in fact, very stressful" (IV03, North and Mid Hampshire ICP)*

They felt this Long COVID-specialist led service would ensure the focus was on the complex, multi-symptom nature of Long COVID, rather than detract from this, which the current model of care was perceived to do. They felt this required a multi-disciplinary approach, including not only healthcare professionals, but also the voluntary sector or organisations and peer representatives.

PREFERENCES FOR INFORMATIONAL SUPPORT

The majority of participants reported they struggled with knowing where to access resources which could offer support for managing their Long COVID, or the best sources of access information, and that they had received little or no guidance regarding this from any healthcare professionals.

Most participants reported the Long COVID service was their preferred service to provide recommendations for resources and sources of information. Some of the participants also felt they would benefit from understanding and being made aware of the resources or information to support them living with Long COVID from others also living with Long COVID.

A) TYPES OF LONG COVID SERVICE INFORMATIONAL SUPPORT AND RESOURCES

Most participants felt the Long COVID service was their preferred contact point to receive information and recommendations for support services, even if they were not support or services provided by the Long COVID service directly. This was underpinned by the participants desire to ensure the information and recommendations they were receiving were from a reliable, knowledgeable, and trustworthy source, and that the information contained be accurate, comprehensive, and relevant.

> *"A lot of people are wary, even of what they put say even on the BBC [about COVID and Long COVID" (IV19, Portsmouth ICP)*

A central point of information and recommendations was proposed, multiple participants indicated the need for a webpage with links to external websites, resources, or app, which was updated periodically to ensure it remained up to date. One participant suggested having a date last updated on the resources provided to information on how contemporary the information and recommendations were.

> *"Rather than having to go and find all this out from different sources, it's all together" (FG09, Portsmouth focus group)*

Some participants suggested having the same information in paper format to ensure information and recommendations for support was also available to those not digitally literate or living in digital poverty.

B) TYPES OF PEER-TO-PEER INFORMATIONAL SUPPORT AND RESOURCES

Some of the participants recognised that the evidence-base for managing Long COVID was sparse and therefore healthcare professionals may not be able to advocate for or recommend support services as a result of this.

Some participants proposed having a 'peer-to-peer' information and recommendations list within a central repository whereby peers can indicate strategies, services, or resources they have accessed which service users otherwise may not hear about.

> *"I'd like to be able to have a search, like if I'm thinking or feeling or noticed something, and see what anyone else has done about it, […], what anyone else has tried or found successful" (IV09, Portsmouth ICP)*

This could help alleviate the frustrations of service users living with Long COVID who may have otherwise been unable to confidently judge the trustworthiness, or who may not have the skillset or energy (due to fatigue and concentration issues) to locate them.

IMPACT AND EXACERBATION OF ANXIETY, GUILT AND GRIEF

All participants reported feelings of anxiety, guilt, and/or grief as result of or as symptoms of their Long COVID. Anxiety, guilt, and grief were felt to be complex symptoms, as some participants saw their anxiety, guilt, and/or grief as a symptom, whereas others felt it was a consequence of their other Long COVID symptoms (potentially seen as a concomitant symptom).

A) ROLE OF SERVICE USER ANXIETY, GUILT, AND GRIEF

Some participants reported anxiety as a symptom itself that needed to be managed whereas others felt they were suffering with insomnia and couldn't sleep, or got severe post-exertional malaise, which then caused them to feel anxious as they were not sleeping, or guilt and grief was due to the malaise and couldn't do what they used to with their children and were grieving their old selves.

> *"I've been getting quite teary, I thought it would be over quickly in the beginning, but that sort of after two or three times [of having a relapse of symptoms], […], when you're looking at the house thinking I can't do that, I've missed that social event, […], I want the old me" (IV12, IOW ICP)*

Regardless of whether their anxiety, guilt or grief was seen as a symptom or consequence, a significant proportion of participants felt anxiety, guilt, and grief impacted upon their ability to self-manage their other Long COVID symptoms (and in some cases were felt to exacerbate their other symptoms more), as well as underpinned the type of support they felt they required.

A significant proportion of participants reported their other symptoms were heightened or exacerbated because of underlying anxiety, guilt and/or grief. This included symptoms of breathlessness, chest pain, insomnia, fatigue (including exercise intolerance and post-exertional malaise), brain fog, memory and concentration problems and muscle and joint aches and pains. Other participants reported that the symptoms they had led them to have feelings of anxiety, guilt, and/or grief.

As a result, participants felt dealing with, monitoring, and receiving support for these psychological symptoms could potentially in turn address the severity of their other symptoms.

B) UNWILLINGNESS TO TREAT LONG COVID AND FEAR OF THE 'UNKNOWN'

Some participants reported an unwillingness of healthcare professionals to treat Long COVID, referring to the newness of the condition, lack of evidence, and their own expertise as rationale for this.

> *"Once you have Long COVID no one wants to know you as it's not their area of expertise" (FG07, IOW focus group)*

Other participants reported that even in the instances where support, services, or advice was offered, it was offered with the caveat of Long COVID being new and complex and that they were unsure of whether any improvements could be made as a result of the support, service or advice offered.

All participants reported this unwillingness to treat and/or 'unknown' factor related to Long COVID management fed into the levels of anxiety and stress they felt.

> *"It's really stressful, knowing yesterday I might have been fine, but today I might not be able to get out of bed" (IV02, North and Mid Hampshire ICP)*
>
> *"It's all about frustration, anxiety and anger, [...], am I going to be disabled forever?" (FG04, IOW focus group)*

The majority of participants reported they understood the newness of Long COVID made it difficult to predict outcomes and provide a prognosis for recovery, but felt this underpinned their desire for support for ongoing symptoms, with check-ins arranged.

The majority of participants also had a desire for support to deal with the fear of the 'unknown'. Supporting people to learn to live with and accept uncertainty was seen as important as managing the symptoms this fear could manifest as (both psychological symptoms such as anxiety or stress, or physical symptoms such as fatigue or headaches).

IMPACT OF CO-MORBID CONDITIONS ON ACCESS TO SUPPORT

Participants differed in how they perceived the impact of co-morbid conditions on referral and access to support services. Some participants reported their co-morbid conditions or severity of the acute COVID they had improved their access to services, or that their ability to self-manage their Long COVID symptoms independently was improved because of co-morbidities.

Other participants reported the presence of co-morbid conditions detrimentally impacted the referrals made or access to clinical services as they were deemed ineligible for some services based upon co-morbidities, or their ability to self-manage and cope independently with their Long COVID.

A) POSITIVE IMPACT

Some participants reported they had pre-established coping and self-management strategies prior to living with Long COVID as a result of having lived with, for example, anxiety, depression, post-traumatic stress disorders, alcoholism, and fibromyalgia in the past.

> *“I had anxiety after I had my two children and at that time I had a lot of therapy, …, that has stood me in really good stead…. I had a toolkit that I could access for Long COVID” (FG03, North and Mid Hampshire focus group)*

Other participants felt having suffered other co-morbid factors (such as a stroke) or having been severely unwell (requiring invasive ventilation) whilst having acute COVID meant they were offered and referred to all the relevant clinical services they required. Despite there being no explicit statements about the converse situation (less severe acute COVID resulting less offerings of support), this was implied as those service users who had less severe acute COVID reported that they didn’t feel their symptoms were taken seriously.

B) DETRIMENTAL IMPACT

Other participants reported that despite having pre-established coping and self-management strategies prior to living with Long COVID as a result of having lived with, for example, anxiety, depression, and fibromyalgia in the past, the impact of Long COVID meant that the symptoms of these conditions were exacerbated and compounded as they felt they were starting from a lower baseline in terms of pre-Long COVID levels of e.g., anxiety, mood or fatigue. Participants also report having co-morbid conditions meant their symptoms were not take seriously and were attributed to these pre-existing conditions, with little or no additional support offered.

> *“When all the results come back negative, or normal, they just go, it’s your anxiety, […], people are literally fighting their doctors to get help” (IV19, Portsmouth ICP)*

A couple of participants also reported the impact of menopause for women of an age where this could be considered as an alternative diagnosis for Long COVID symptoms, and as a result meant the support services offered to manage the Long COVID symptoms could be detrimentally affected.

PEER SUPPORT

All participants felt peer support was essential, that it would or had reduced their feelings of isolation, and that it would or had reduced their concerns that their symptoms were ‘made-up’, stopping them feeling like they were ‘going mad’.

> *“It's really difficult for people to understand, […], 'it all sounds really silly to people” (IV01, North and Mid Hampshire ICP)*
>
> *“People either don’t believe you, or it affects you, […], so it becomes like your dirty little secret” (IV19, Portsmouth ICP)*

> *"I wish this group thing had happened 6 months ago" (FG07, IOW focus group)*

The majority of participants felt a peer-led peer support service, which offered both a 1:1 and group peer support, was preferrable. Most participants felt this catered for individual preferences. It was also reported that a combination of virtual (telephone and online) as well as a face-to-face peer support offering would be required to allow for individual preferences.

All participants who advocated for peer support felt they would benefit from peer support if it was offered in a way which meant peers could be matched based upon characteristics important to the individual and where you lived.

> *"It would be good to get to know people locally because that would be quite good support" (IV01, North and Mid Hampshire ICP)*

The characteristics participants suggested to be important to be matched according to include the types of symptoms experienced, what they were looking for from peer support (e.g., group to offload to who understood Long COVID or to provide a positive space to share recommendations to manage symptoms), and length of time with long covid (could be of similar timeframe to provide reassurance, or mentor-mentee type model depending on desires of the individual).

One participant was an administrator on a Long COVID support group on Facebook. This participant reported the value the peer support online provided, however also reported having a lack of knowledge of how to appropriately support peers posting online. This participant felt support and guidance from healthcare professionals for the lay administrators of online support regarding where to signpost people living with Long COVID would be beneficial (e.g., basic advice on what voluntary or local support services to suggest if someone posts about feeling low in mood or anxious etc within a Facebook group).

IMPACT OF PRIVATE HEALTHCARE AND SELF-FUNDING ON ACCESS TO SUPPORT

Some participants reported having private healthcare which offered additional support for those living with Long COVID, or personally opted to self-fund e.g., councillors, to increase their access to support they felt they required but was not available to them.

> *"I'm hoping that now we're a bit more aware of Long COVID that accessing services will be easier for all but certainly my husband having the job he's got has allowed to move my recovery forward [as he had private healthcare for family]" (FG03, North and Mid Hampshire focus group)*

All participants who discussed accessing or self-funding to expand the support and care available to manage their Long COVID symptoms felt it should not be necessary to have to have private healthcare or the wealth or financial means to be able to do this, and that the services accessed were support which should be available to all those living with Long COVID, not just those with the advantage of having the finances to be able to afford them.

EMPOWERMENT AND POSITIVITY TO INDEPENDENTLY SEEK SUPPORT

There were trends to suggest participants who were more empowered had two things in common: 1) positivity (looking for solution to overcome their symptoms as opposed to waiting for 'cures' to be offered), and 2) confident in their own ability to independently seek support offerings to self-manage their Long COVID symptoms.

> *"I did quite a lot of research, […], getting into news reports and things online, getting into the BMJ, there was quite good stuff in the guardian quite frequently, […], wanting to know how to make myself better" (IV02, North and Mid Hampshire ICP)*

This positivity and confidence appeared to be greater in those participants from North and Mid Hampshire and one participant from Portsmouth, who all higher index of multiple deprivation, indicating those less deprived were potentially more likely to have accessed a greater number of support services independently.

SPECIFIC SUPPORT REPORTED BY PARTICIPANTS

Underpinning the identified themes was a wide range of specific examples of support. The types of support for Long COVID reported in the survey, interviews, and focus groups are detailed below in Table 9. Each provider and ICP could consider reviewing the types of support reported within Table 9 and potentially use this as a basis for developing informational support for service users.

The three different types of support reported:

1. Support people **received or self-sought** (defined as support services which were a) received or referred to, or b) that had been self-sought and available)
2. Support people **felt was essential** (defined as support services which were felt to the minimum Long COVID services to offer, but that were not currently offered or referred for)
3. Support people **felt was desirable** (defined as support services which were felt to be required for Long COVID service to be fully holistic and comprehensive, but were not currently offered or referred for)

Although there appeared to be nuances in the care reported to have been received between the different ICPs and some variation that may be related to pre-existing services commissioned in the ICPs, the essential and desired services of the participants across the ICPs were found to be broadly similar. Some of the nuances included more accessible mental health support offerings in Portsmouth compared to North and Mid Hampshire and IOW, whereas North and Mid Hampshire appeared to have more fatigue management and general self-management advice available.

It is also important to note that a large proportion of the 'self-sought' support was sourced by participants living in North and Mid Hampshire, and that participants reported multiple 'self-sought' avenues for support. For those outside of North and Mid Hampshire who sought out and had been successful in seeking additional avenues for support, it was only a few participants who reported these, and like those in North and Mid Hampshire, they reported seeking out support from multiple avenues.

Table 9. The types of support people 1a) received or 1b) self-sought, 2) felt were essential, and 3) felt were desirable from the surveys, interviews, and focus groups

Type of support*	**Examples**	**Data source**
1. a) Support people received	**Referred for or recommended by healthcare professionals:**	
	• 'Your Covid recovery' and 'Living with' app: https://www.yourcovidrecovery.nhs.uk/ https://www.livingwith.health/products/covid-recovery/	I & FG; S
	• Steps to wellbeing service https://www.steps2wellbeing.co.uk/	S
	• Local authority helpline	S

	• Mental health (virtual / telephone / app) programmes and/or counselling (virtual and face-to-face) (iTalk; Talking Change; Talking Therapies; private counselling [unknown providers] and psychotherapy [including Physiotherapy mental health unit and Primary Care Mental Health team])	I & FG; S
	• Medical reviews (general practitioner; respiratory; cardiology; neurological [private and NHS]; gastroenterology; rheumatology [private]; dermatology; chronic fatigue)	I & FG; S
	• Non-medical professional reviews (physiotherapy; occupational therapy; social services [including reablement]; dietetics; speech and language therapy)	I & FG; S
	• Specialist Long COVID service referrals (Hobbs Rehabilitation Clinic [private] and NHS)	I & FG
	• Sleepio app (insomnia) https://www.sleepio.com/#howSleepioWorks	I & FG
	• Fatigue management advice (pacing; boom-bust cycle)	I & FG
	• Co-morbid condition support groups (stroke – unnamed group)	I & FG
	• Occupational health services	I & FG; S
	• Human Resources support (e.g., keeping workplace updated and workplace rehabilitation support)	S
	• Research projects: Portsmouth Long COVID Study Coverscan research project including webinars: https://perspectum.com/news/perspectum-launches-the-first-covid-19-recovery-study	S
1. b) Support people self-sought	**Self-sought and available:**	
	• Personal training / physiotherapy / exercising (unnamed sources)	I & FG; S
	• Restorative yoga (unnamed sources)	I & FG
	• Walking groups (unnamed sources)	I & FG
	• Walking App (unnamed)	S
	• Swimming / aqua aerobics (unnamed sources)	I & FG
	• Chiropody (unnamed source)	S
	• Massage	S
	• Counselling (private)	I & FG; S
	• Social media support groups and advice forums (e.g., Facebook Long COVID Support Forum; Facebook group for doctors with Long COVID [unnamed]; Long COVID Instagram pages [unnamed]) 'AbSent': https://www.facebook.com/AbScent.org/ https://www.facebook.com/groups/longcovid/	I & FG; S
	• ShutEye app (sleep quality monitoring) https://www.shuteye.ai/	I & FG
	• ZOE COVID app (symptom monitoring) https://covid.joinzoe.com/about	I & FG; S

	• Gupta programme https://www.guptaprogram.com/	I & FG; S
	• YouTube and other online Long COVID bloggers and podcasters (some unnamed sources) Gez Medinger: https://www.youtube.com/channel/UCln_SCEd4JiGkHIUZd1VlXw	I & FG; S
	• TV documentaries (unnamed source)	S
	• Online / virtual exercise and stretching programmes (unnamed sources)	I & FG
	• Support groups (for both the person living with Long COVID and their direct family members) https://www.vosuk.org/about-us/	I & FG
	• Chronic fatigue syndrome and fibromyalgia information and advice (for both the person living with fatigue / post-exertional malaise and their family and friends)	I & FG
	• Spiritual guidance	S
	• Relaxation techniques (e.g., Yoga, Tai Chi, Mindfulness)	S
	• Breathing classes	S
	• Long Covid and ME/CFS Holistic Healing Summit 2021	S
	• Complementary therapies and remedies (herbal teas; oral tablets; vitamins; B12 injections; reflexology; acupuncture)	I & FG; S
	• Voluntary services Solent MS therapy centre: https://solentmstc.org.uk/ Just About You Home Help (Age UK, Isle of Wight): https://www.ageuk.org.uk/isleofwight/our-services/just-about-you-home-help/	S
2) Support people felt were essential	• Peer-support	I & FG
	• Feedback from symptom diaries to better self-manage / understand triggers	I & FG
	• Periodic follow-up with Long COVID specialists	I & FG
	• Long COVID specific education / advice for: ▪ Reduced ability to conduct activities of daily living ▪ Exercise / physical activity / post-exertional malaise ▪ Fatigue management (including work activities / tasks) ▪ Navigating and applying for financial support available (inc. disability badges) ▪ Non-Long COVID specialist healthcare professionals ▪ Employers and colleagues ▪ Family and friends ▪ Stress management (and to deal with underlying stressors) ▪ Guilt management (and to deal with the underlying reasons for guilt) ▪ Grief management (and to deal with underlying reasons for grief) ▪ PTSD / fear management (and to deal with underlying reasons for PTSD)	I & FG

	• Dealing with loneliness / social isolation	I & FG
	• Wider connections with voluntary sector (e.g., Mind)	I &FG; S
3) Support people felt were desirable	• Education / resources for community managers and admins for online or social media peer support groups	I & FG
	• Identifying / lobbying for ongoing local financial support like a Furlough scheme, but for those with Long COVID	I & FG

**This table reports the types of support reported by all participants, even if only reported by one participant, therefore this table is a representation of the collective experiences and may not be reflective of each individual participants experiences; this table is not in order of perceived level of importance for participants or in chronological order according to number of times reported; this table merges support offering and does not specifically distinguish support according formal NHS healthcare services, private healthcare, Human Resource services and voluntary sector support offerings, although this is included when known.*

Abbreviations: I & FG = interviews and focus groups; S = survey.

EVALUATOR REFLEXIVITY AND PARTICIPANT FEEDBACK POST-INTERVIEWS AND FOCUS GROUPS

Following the interviews and focus groups, feedback was received from multiple participants regarding the benefits and relief they had experienced after having the opportunity to discuss their COVID journey and living with Long COVID, showing the value in being listened to. One interviewee stated:

> *“To report how difficult it has been seems to have lifted a load off my mind. I have been able to walk further than before, didn’t have a rest yesterday afternoon for one of the few occasions since March 2020 and my spirits seem to be lifting”*

Another participant from the focus groups also reported similar feelings:

> *“Please can I thank you and your colleagues for inviting me to participate in yesterday’s evaluation session. I cannot express how much hope and inspiration it gave me in believing that the aftermath, which some people suffer with this awful virus, is being recognised.”*

Those conducting the interviews and focus groups also made some reflections following each event as part of the process for recording field notes. One evaluator reflected on the power of simply speaking with others living with Long COVID, and the relief this had brought them. Another evaluator’s reflections corroborated this, suggesting participants had felt significant benefits of being able to share similar lived experiences with people.

After the third focus group, an evaluator reflected that the dynamic within the three focus groups all differed. The participants in the third focus group felt much more heterogeneous than the previous two focus groups from multiple perspectives. First, it was felt that their experiences of living with Long COVID were different. Second, it was felt they had a wide variation of previous co-morbid physical and mental health condition. Finally, it was felt they had disparate views of how to seek support (whether to self-seek or to be recommended by healthcare professionals). Therefore, although it was clear the participants found speaking to others with Long COVID helpful, it was also felt that due to the heterogeneity, that they weren't inherently drawn to each other to keep in contact after the focus group as much as was found in the previous two focus groups. It was reflected that one of the participants would have had a more similar lived experience of Long COVID to those in the first focus group. Likewise, another participant in the third focus group was felt to have a more similar mentality and outlook to the participants in the second focus group with regards to strategies for seeking support.

SYNTHESISED FINDINGS

The age, gender, ethnicity, employment status and reported symptoms were similar between the respondents who completed the survey and for the participants who took part in the interviews and focus groups. There was however slightly different representation of the six ICPs between the survey respondents and the participants from the interviews and focus groups; Portsmouth, IOW, Southampton, and South and East Hampshire were represented by the survey respondents whereas Portsmouth, IOW, North and Mid Hampshire and South and East Hampshire were represented by the interview and focus group participants.

It is important to note the ethnic diversity of the group represented in this evaluation was limited, therefore the transferability of the findings in this report to other ethnic groups may be limited too. It would also be important to better understand whether the perspectives and experiences of the ICPs not represented within this evaluation corroborate those from the ICPs included.

There was overlap between survey responses and the main themes of: 1) preferences for delivery of support (sub-themes: human and face-to-face contact with healthcare professionals; regular, structured, and expeditious contact with healthcare professionals; model for delivering support), 2) preferences for informational support (sub-theme: types of Long COVID service informational support and resources), 5) peer support, and 6) impact of private healthcare and self-funding on access to support. These data were either confirmatory or complementary, meaning that the survey respondents and interview and focus group participants were reporting similar perspectives or support needs between the two separate sets of findings.

In addition, there appeared to be no evidence of refutation between any survey data and themes derived from the interviews and focus groups. This indicates there was little divergence between survey respondents and interviews or focus group participants.

In the instances where the data was not present in both data sets, it was classified as ‘silent’. There was silence with the survey for the main themes ‘impact and exacerbation of anxiety, guilt, and grief (sub-themes: role of service user anxiety, guilt, and grief; unwillingness to treat Long COVID and fear to the ‘unknown’), ‘impact of co-morbid conditions on access to support‘ (sub -themes: positive impact and detrimental impact), ‘empowerment and positivity to independently seek support’, and the sub-theme ‘types of peer-to-peer informational support and resources’ from interviews and focus groups. This means no respondents to the survey provided responses which link with these themes. This is not unexpected given the interviews and focus groups afford the opportunity to probe participants perspectives, which in turn allows for a richer, deeper understanding of underlying feelings.

Having synthesised the survey, interview, and focus group findings, the evaluation team inferred four additional findings (termed meta-themes): (1) Optimising care between referral and assessment: ‘Make Every Wait Count’, (2) Accessible model of care, (3) Comprehensive, holistic assessment leading to individually tailored management plans, (4) Deprivation and clinical decision-making considerations.

META-THEME 1: OPTIMISING CARE BETWEEN REFERRAL AND ASSESSMENT: 'MAKE EVERY WAIT COUNT'

From reviewing all available service users' views, it was clear the need for resources and information sharing during the period between referral to the Long COVID service and assessment was essential for service users to feel supported. Information and resources were felt to be required not only to improve service users' ability to self-manage and seek peer or voluntary support but also to support or enhance the offer of support from family, friends, and employers.

META-THEME 2: ACCESSIBLE MODEL OF CARE

The collation of service users' views indicated an accessible model of care was considered essential and a hybrid approach of both face-to-face and virtual or online assessment would be optimal. This could manage symptoms (and symptoms variation) in the instance attending face-to-face exacerbates anxiety, fatigue or transport is an issue, whilst also offering a preferred method of delivery (face-to-face). This could be followed up with ongoing monitoring for periodic 'check-ins' monitoring. Service users reported these factors as essential given the unknown nature of Long COVID recovery and the perceived risk of symptom relapse.

META-THEME 3: COMPREHENSIVE, HOLISTIC ASSESSMENT LEADING TO INDIVIDUALLY TAILORED MANAGEMENT PLANS

The collation of service users' views indicated a comprehensive holistic assessment was important to establish each individual service user's presentation of Long COVID. A comprehensive holistic assessment would be used to inform the development of management plans tailored to each individual service user's symptoms and needs.

META-THEME 4: DEPRIVATION AND CLINICAL DECISION-MAKING CONSIDERATIONS

The collation of service users' views indicated service user geographic deprivation level may be an important consideration in the type of Long COVID support offered. Clinical decision-making by healthcare professionals regarding the support offerings for each individual service user is likely to be informed by multiple factors (e.g., symptoms reported, severity of symptoms, co-morbidities, digital literacy etc.). However, this report has highlighted indicative findings that healthcare professionals could consciously consider level of deprivation alongside other factors. There were indictive findings to suggest those with a lower level of deprivation were more able to 'self-seek' support. Although this needs further evaluation to better understand the relationship between level of deprivation and level of empowerment or confidence to seek support, 'self-sought' support was predominantly reported by participants living in the less deprived area of North and Mid Hampshire ICP. Survey findings corroborate this as IOW and Portsmouth appeared disempowered or uncertain of how to support themselves (20% did not answer question, a further 20% explicitly stated they dd not seek support independently) and would support the indicative findings from the interviews and focus groups.

CONCLUSIONS

1. The service-wide survey indicated a considerable number of service users on the Long COVID caseload are either not empowered to identify support or it is not currently detectable or available. It was clear a publicly visible Long COVID service has yet to be established and more could be done to advertise its support offer.
2. Long waits for assessment by the Long COVID service were reported. Service users desired more information and/or discussion with clinicians, in the gap between referral and assessment, to inform and support current symptoms.
3. Service users reported a wide range of support as either received, wanted, essential, or desired. The information provided could inform the Long COVID service activities in the future.
4. Service users perceived limited formalised NHS support and embryonic community-based support. This led to a heavy reliance on family, friends, and employers for support. It also led to some seeking private health care to support symptoms of Long COVID. As a result, a disparity in support accessible to service users living with Long COVID is likely due to personal circumstances (availability of family, friends, finances) and should be considered.
5. The predominance of ‘contact’ and sharing experiences was a powerful message across the 139 survey respondents and the 28 participants interviewed or in focus groups. Multiple support forums were requested (peer-to-peer and clinician-facilitated) and it would appear prudent to consider how these can be started and sustained as part of formalised NHS support.
6. Participants reported peer support to be invaluable and paramount to them being able to rationalise and live with Long COVID.
7. The complexity and breadth of reported symptoms highlighted the need to ensure a consistent, holistic assessment and management plan is undertaken, with information and resources given early (at the point a referral to the Long COVID service is accepted) with a central, specialist service co-ordinating the management plan. This was perceived by service users as a strategy to enhance support for and reduce burden on those living with Long COVID.
8. Based on all available service users’ views, it would appear the Long COVID service ‘offer’ across the ICPs could be enhanced to support the diverse and complex nature of the symptoms reported.

CONSIDERATIONS FOR LONG COVID SERVICE COMMISSIONERS

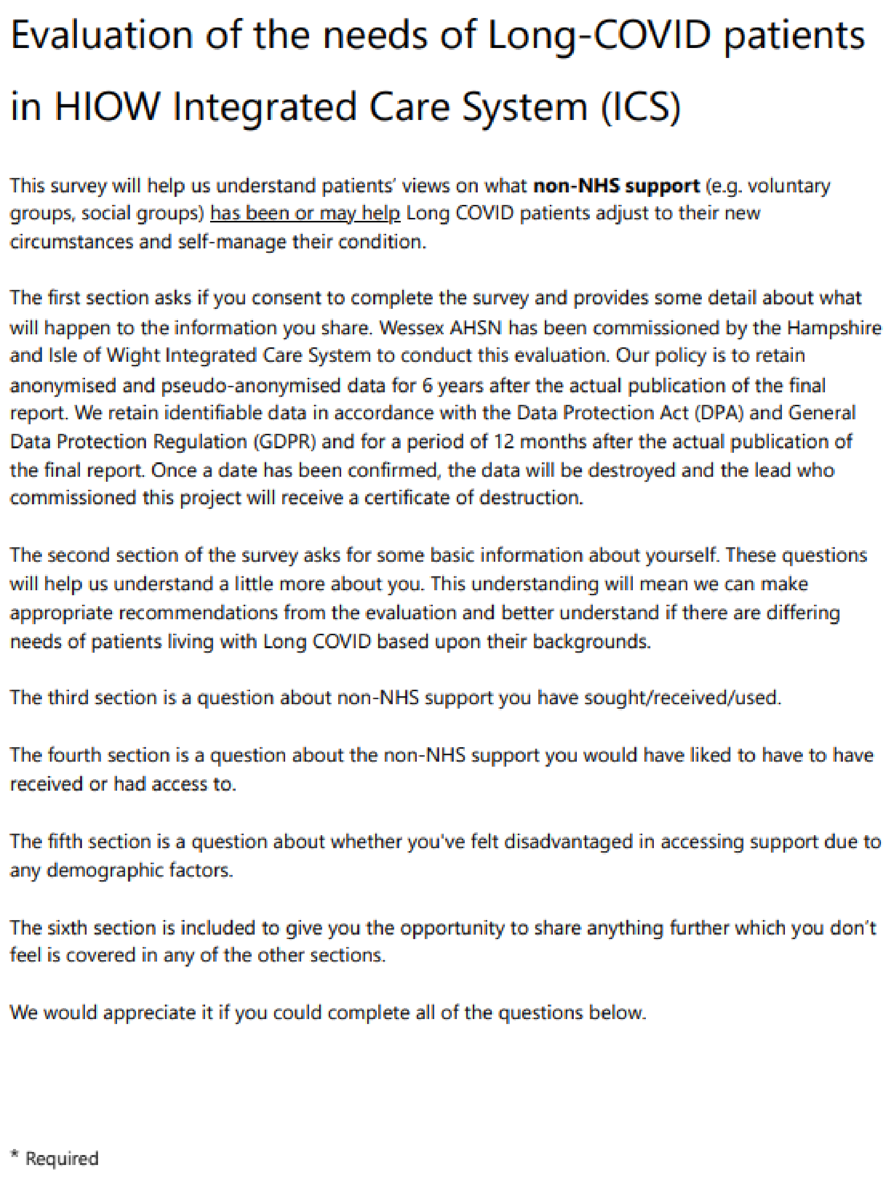
Based on the findings in this evaluation, the Strategic Long COVID Group may wish to consider the following to enhance the current activities of the Long COVID service and inform commissioning plans.

1. **Empowerment of service users:** recognise and acknowledge empowerment levels as an influential force in the management of Long COVID. Strategies to empower, e.g., improving digital literacy and reducing digital poverty, should be considered as important as any information passed onto service users.
2. **Types of support to start and sustain, that could include:** both virtual and face-to-face peer-led and clinician-led support groups, development of a training and a competency framework for peer-led (‘expert patient’) support groups, Long COVID Public and Patient Group, Long COVID crisis support mechanism, and a maintained information repository for multiple stakeholders.

3. **'Making every wait count'**: Due to current resource limitations, long wait times for assessment and the likelihood of an increasing Long COVID caseload, using the time between referral and assessment could be a key focus moving forward. Using this time to inform and empower service users would support their needs and avoid crisis points. There is potential for a coordination role to support action during these wait times.
4. **Models of support:** based on the evaluation findings, a multi-component model (virtual central hub approach) is proposed in Appendix 2. This model suggests multiple layers of informational support in between referral and assessment, involvement of a range of professionals potentially through a Multi-Disciplinary Team forum (MDT), training for key professionals to become Long COVID specialists, and a review process that reflects the relapsing-remitting nature of Long COVID symptoms.
5. **Enabling good connections with available voluntary sector support:** service users could benefit from an awareness of voluntary sector support. This could relate to any symptom reported by service users living with Long COVID, for example mental health support (e.g., MIND), manging fatigue (signposting to guidance provided for other conditions such as chronic fatigue syndrome), guidance on eligibility and support to submit applications for finance support (e.g., from local authority), home help or day to day support (e.g., Age UK) or addressing loneliness and isolation (e.g., Age UK). Due to different voluntary sector landscapes in each provider region, information and resources would benefit from being 'ICP-specific' as well as HIOW-wide. It could enable service users to have access to a broad network of support to access beyond that provided by NHS healthcare professionals.
6. **Optimising healthcare professional-service user interactions:** it was service users' wish that Long COVID service clinicians were experts in this area. Regular training in and reviews of the Long COVID evidence base would support that need. Geographical deprivation level was identified as a factor that may affect service users' ability to seek support independently or their choice of support. Being employed appeared to be related to higher levels of reported symptoms. These could be considered during clinical decision-making and tailoring of management plans.
7. **Further insight generation about users' experiences and needs:** due to the limited evidence base on how service users seek/use/desire support, further insight generation could inform ongoing service development. This could be facilitated through ICS-wide meetings to share learning and by inviting researchers to study and present findings to the Strategic Long COVID Group.

APPENDICES

APPENDIX 1: LONG COVID SERVICE-WIDE SURVEY



Evaluation of the needs of Long-COVID patients in HIOW Integrated Care System (ICS)

This survey will help us understand patients' views on what **non-NHS support** (e.g. voluntary groups, social groups) has been or may help Long COVID patients adjust to their new circumstances and self-manage their condition.

The first section asks if you consent to complete the survey and provides some detail about what will happen to the information you share. Wessex AHSN has been commissioned by the Hampshire and Isle of Wight Integrated Care System to conduct this evaluation. Our policy is to retain anonymised and pseudo-anonymised data for 6 years after the actual publication of the final report. We retain identifiable data in accordance with the Data Protection Act (DPA) and General Data Protection Regulation (GDPR) and for a period of 12 months after the actual publication of the final report. Once a date has been confirmed, the data will be destroyed and the lead who commissioned this project will receive a certificate of destruction.

The second section of the survey asks for some basic information about yourself. These questions will help us understand a little more about you. This understanding will mean we can make appropriate recommendations from the evaluation and better understand if there are differing needs of patients living with Long COVID based upon their backgrounds.

The third section is a question about non-NHS support you have sought/received/used.

The fourth section is a question about the non-NHS support you would have liked to have to have received or had access to.

The fifth section is a question about whether you've felt disadvantaged in accessing support due to any demographic factors.

The sixth section is included to give you the opportunity to share anything further which you don't feel is covered in any of the other sections.

We would appreciate it if you could complete all of the questions below.

* Required

1. Our policy is to retain anonymised and pseudo-anonymised data for 6 years after the actual publication of the final report. We retain identifiable data in accordance with the Data Protection Act (DPA) and General Data Protection Regulation (GDPR) and for a period of 12 months after the actual publication of the final report. Following these retention periods the data will be destroyed.
Are you happy to complete the survey and for your data to contribute to the final report and be held/destroyed in this way?
*

○ Yes

○ No

Section 2

Demographic questions

Your responses to these questions are important to capture, as they will allow us to understand how people in different circumstances may have different experiences.

2. In which region is the Long COVID service locality you have been referred to? Please refer to your invite letter if you are unsure of your Long COVID service locality. *

○ Mid and North Hampshire

○ West Hampshire

○ South and East Hampshire

○ Southampton

○ Portsmouth

○ Isle of Wight

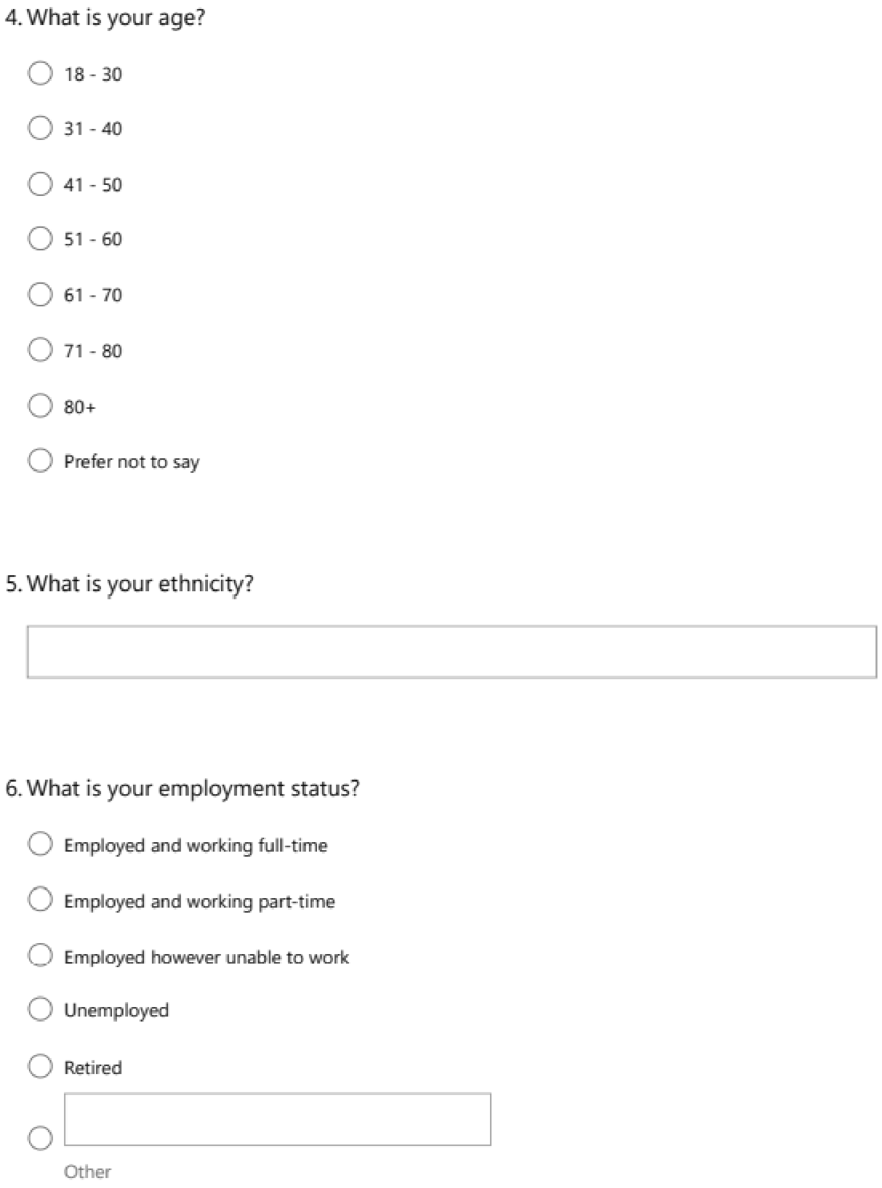
3. What is your gender?

○ Male

○ Female

○ Gender diverse

○ Prefer not to say



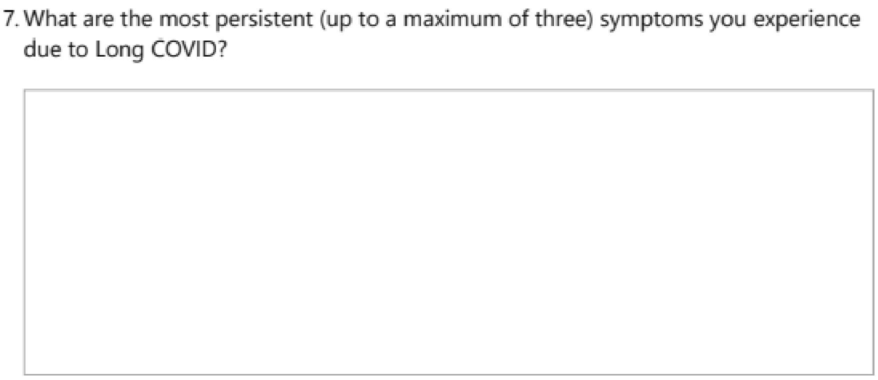
4. What is your age?

- ○ 18 - 30
- ○ 31 - 40
- ○ 41 - 50
- ○ 51 - 60
- ○ 61 - 70
- ○ 71 - 80
- ○ 80+
- ○ Prefer not to say

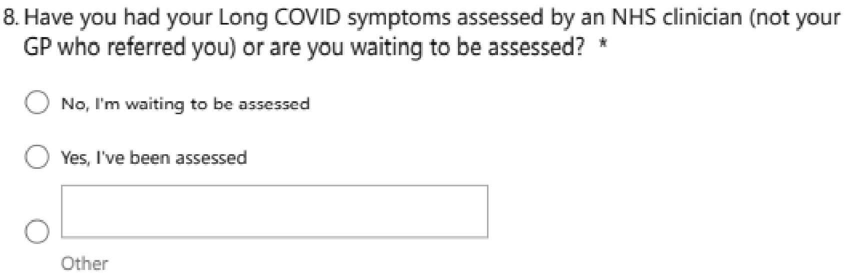
5. What is your ethnicity?

6. What is your employment status?

- ○ Employed and working full-time
- ○ Employed and working part-time
- ○ Employed however unable to work
- ○ Unemployed
- ○ Retired
- ○ Other



7. What are the most persistent (up to a maximum of three) symptoms you experience due to Long COVID?

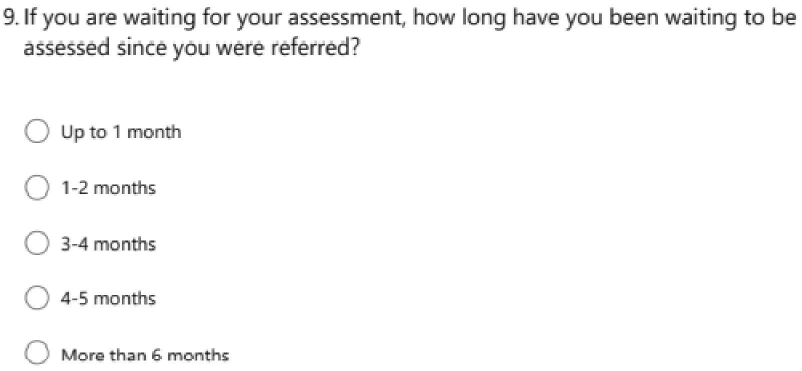


8. Have you had your Long COVID symptoms assessed by an NHS clinician (not your GP who referred you) or are you waiting to be assessed? *

○ No, I'm waiting to be assessed

○ Yes, I've been assessed

○ Other



9. If you are waiting for your assessment, how long have you been waiting to be assessed since you were referred?

○ Up to 1 month

○ 1-2 months

○ 3-4 months

○ 4-5 months

○ More than 6 months

Section 3

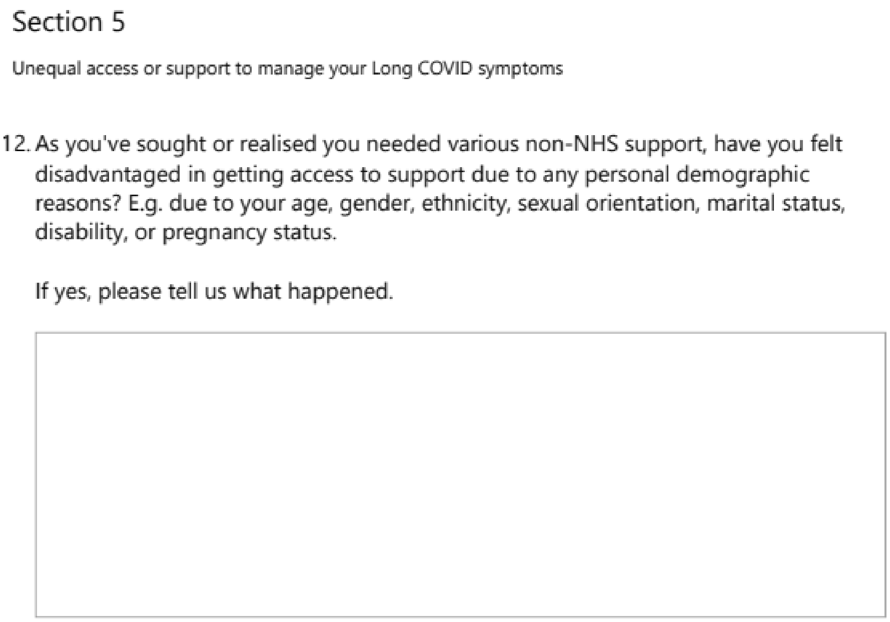
Tell us about services you've found useful/not useful

10. Whilst you've been waiting for formal NHS services to support your symptoms/impact of Long COVID, please tell us what non-NHS support **you have sought/received/used** (e.g. from voluntary organisations, social organisations, from family/friends). This information will be of great help to other people living with Long COVID (If you have not sought or received any non-NHS support, please move onto the next question).

Section 4

What support would you like?

11. Whilst you've been waiting for formal NHS services to support your symptoms/impact of Long COVID, please tell us what non-NHS support **you would like** (e.g. from voluntary organisations, social organisations, from family/friends). This will help us to identify any key areas where non-NHS support services could be improved.

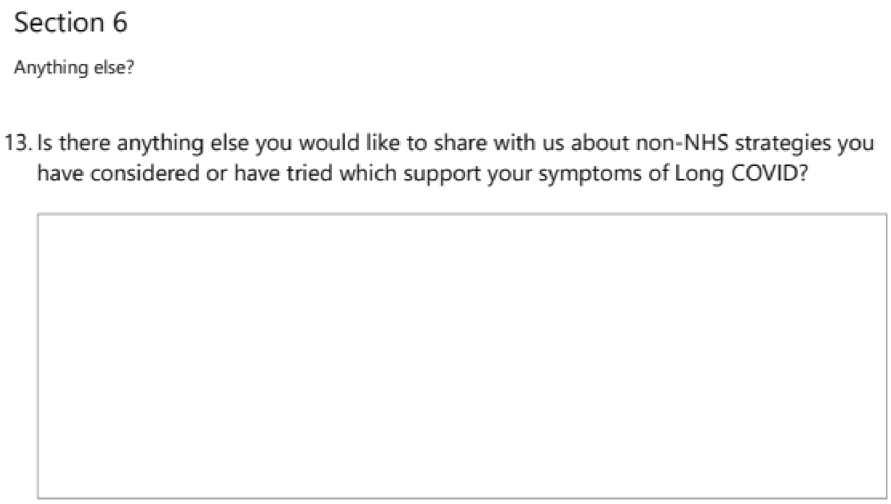


Section 5

Unequal access or support to manage your Long COVID symptoms

12. As you've sought or realised you needed various non-NHS support, have you felt disadvantaged in getting access to support due to any personal demographic reasons? E.g. due to your age, gender, ethnicity, sexual orientation, marital status, disability, or pregnancy status.

If yes, please tell us what happened.

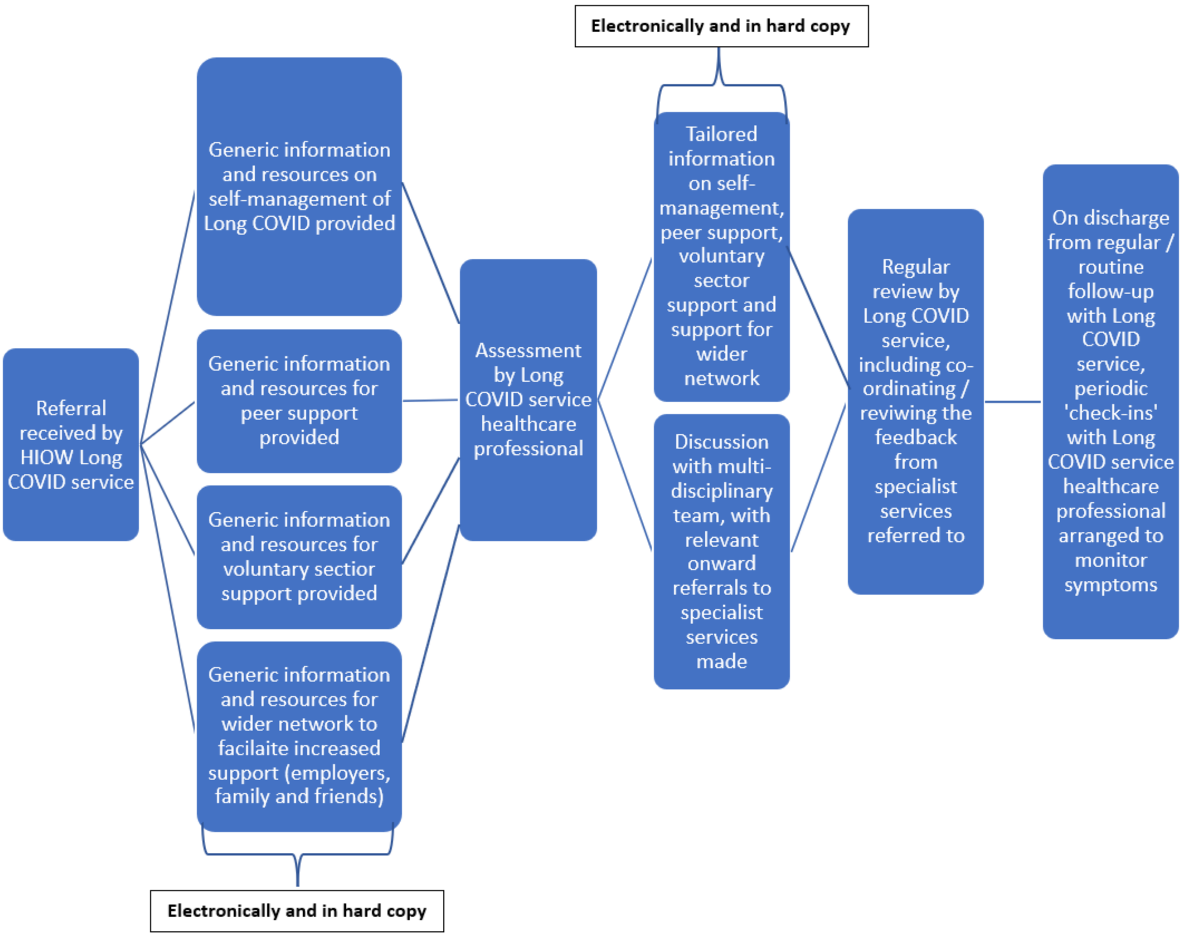


Section 6

Anything else?

13. Is there anything else you would like to share with us about non-NHS strategies you have considered or have tried which support your symptoms of Long COVID?

APPENDIX 2: PROPOSED LONG COVID SERVICE MODEL OF CARE BASED UPON THE EVALUATION FINDINGS



VERSION CONTROL

Version	Status	Key Changes	Authorised by
1	Completed		AS
2	Submitted to client		PD
3	Final version submitted to client		PD