



Patient symptoms and experience following COVID-19: results from a UK-wide survey

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ABSTRACT

Objectives To investigate the experience of people who continue to be unwell after acute COVID-19, often referred to as ‘long COVID’, both in terms of their symptoms and their interactions with healthcare.

Design We conducted a mixed-methods analysis of responses to a survey accessed through a UK online post-COVID-19 support and information hub, between April and December 2020, about people’s experiences after having acute COVID-19.

Participants 3290 respondents, 78% female, 92.1% white ethnicity and median age range 45–54 years; 12.7% had been hospitalised. 494 (16.5%) completed the survey between 4 and 8 weeks of the onset of their symptoms, 641 (21.4%) between 8 and 12 weeks and 1865 (62.1%) >12 weeks after.

Results The ongoing symptoms most frequently reported were: breathing problems (92.1%), fatigue (83.3%), muscle weakness or joint stiffness (50.6%), sleep disturbances (46.2%), problems with mental abilities (45.9%), changes in mood, including anxiety and depression (43.1%) and cough (42.3%). Symptoms did not appear to be related to the severity of the acute illness or to the presence of pre-existing medical conditions. Analysis of free-text responses revealed three main themes: (1) experience of living with COVID-19: physical and psychological symptoms that fluctuate unpredictably; (2) interactions with healthcare that were unsatisfactory; (3) implications for the future: their own condition, society and the healthcare system, and the need for research

Conclusion Consideration of patient perspectives and experiences will assist in the planning of services to address problems persisting in people who remain symptomatic after the acute phase of COVID-19.

INTRODUCTION

The COVID-19 pandemic is one of the most important public health crises of recent history, with substantial impacts on human health and well-being, related both to the direct effects of the condition and the impact of measures to control and reduce infection.^{1–3} Though many people have asymptomatic infection,⁴ others develop COVID-19 disease. Severity of the initial phase varies

Key messages

- What is the experience of having long-term effects of COVID-19 like for people with this condition, particularly in those who were not admitted to hospital during the acute phase of their illness.
- The findings from our study, in a large population, many of whom were not hospitalised during the acute phase of their illness, demonstrate the varying patterns and persistence of symptoms of long COVID, which do not appear to be associated with severity of the acute phase of the disease or pre-existing medical conditions. Qualitative findings also enrich the understanding of the patient experience of long COVID symptoms, healthcare interactions and suggestions for future research and service adaptation
- Patient experience should inform the development of services to support people with long COVID and shape follow-up care and management strategies. This will help to address the sense that patients have of being unheard and reassure them that they are being taken seriously, regardless of severity of the acute phase of their initial illness.

dramatically between individuals, from mild flu-like symptoms to multiorgan failure and death.^{5,6} The pandemic response has largely focused on reducing hospitalisation and mortality from acute COVID-19⁷; however, a substantial proportion of people experience long-term symptoms.^{8–14}

As a relatively new and complex phenomenon, the syndromes and terminology involving persisting symptoms following acute COVID-19 are inconsistently defined.¹⁵ A recent National Institute for Health and Care Excellence (NICE) clinical guideline for the management of people with symptoms following COVID-19 subcategorises this into ‘ongoing symptomatic COVID-19’ for people with persistent symptoms 4–12 weeks after the start of acute COVID-19 and ‘post-COVID-19 syndrome’ for those whose



symptoms have not resolved 12 weeks after the onset of acute COVID-19.¹⁶ Persisting symptoms are likely to be underpinned by a range of processes that are yet to be fully established, including organ damage, cognitive processing disorders, autonomic dysfunction and continuing inflammatory response and/or blood clotting disorders.¹⁵ In this paper, we use the term 'long COVID', which appears popular among people experiencing prolonged symptoms, with some also adopting the phrase 'long-haulers'.^{16–18}

We analysed responses to an online survey of people with long COVID to explore symptom frequency, patient experience and identify key themes to improve understanding of the condition and inform healthcare responses.

METHODS

We used a mixed methods approach, combining quantitative and qualitative methods, to analyse data from a UK wide survey conducted in April 2020, via an online Post-COVID hub <https://www.post-covid.org.uk/>. The survey asked respondents about the presence and duration of symptoms, the level of treatment they had required during their initial COVID-19 illness (eg, at home or in hospital) and their experience of care, support and information received during and after this.

Thematic analysis of free-text responses to the questions 'How would you describe your experience after COVID-19?' and 'Please describe what kind of follow-up support you would ideally like to receive from your healthcare providers' was undertaken by SB, PW and KEJP based on the approach described by Braun and Clarke.¹⁹ Additional details of the survey and thematic analysis are available in online supplemental file 2.

Statistical analyses were performed using SPSS V.27. Demographic data and information about pre-existing health conditions were collated and presented by groups according to the level of treatment received during the initial phase of the illness (community vs hospitalised). Statistical testing was also carried out to investigate any differences in symptoms between those reporting pre-existing health conditions (ie, breathing problems in those with respiratory disease or mood disorders in those with existing mental health diagnoses), compared with those who did not. Between-group differences were compared using χ^2 test or independent t-tests as appropriate, with $p < 0.05$ taken to indicate statistical significance. Where there were ordinal variables (eg, age groups) a midpoint of each category was taken to allow statistical testing to be performed. For categories with very small numbers, adjacent categories were collapsed together to allow for comparison. In the case of duplicate entries, the most recent was used for analysis.

Participants were required to give informed consent for the use of their data for this purpose at the start of the survey.

Patient and public involvement

Patients and members of the public were not specifically involved in the design, conduct or reporting of this research, and study participant validation of the themes was not possible due to the nature of data collection methods used; however, the findings were discussed with, and reviewed by, expert patients with long COVID.

RESULTS

There were 3648 responses between 28 April 2020 and 15 December 2020 which, excluding 273 blank entries and 85 duplicates, left a final sample of 3290 for analysis (table 1). Seventy-eight per cent of respondents were female, 92.1% reported white ethnicity and the most frequently represented age range was 45–54 years. A total of 2873 (87.3%) had remained at home during their acute illness and 417 (12.7%) had been admitted to hospital for treatment. The prevalence of asthma in our cohort was high (26.3%) in comparison with other pre-existing conditions.

The most frequently reported symptoms were breathing problems (92.1%), fatigue (83.3%), muscle weakness or joint stiffness (50.6%), sleep disturbances (46.2%), problems with mental abilities (45.9%), changes in mood, including anxiety and depression (43.1%) and cough (42.3%). There was no statistical difference in symptom pattern between those who had been hospitalised and the rest of the survey population (figure 1/online supplemental table E1).

Respondents most frequently reported five to seven coexisting symptoms (40.1%) with a mean (SD) of 5.0 (2.3) (figure 2). People with pre-existing lung disease (27.6%) were more likely to report post-COVID-19 breathing problems compared with those without, although the difference was numerically small (88.4% vs 83.7%; χ^2 11.6, $p=0.001$). Changes in mood were commonly reported; however, there was no significant difference between those with or without pre-existing anxiety and/or depression (24.7% vs 22.4%) (χ^2 1.262, $p=0.261$).

Two hundred and seventy respondents (8.2%) completed the survey <4 weeks after the onset of symptoms, 494 respondents (15.0%) between 4 and 8 weeks of the onset of their symptoms, 642 (19.5%) between 8 and 12 weeks and 1865 (56.7%) completed the survey after 12 weeks of symptom onset. The demographics of people completing the survey at different time points were similar, with a tendency for increase in age as duration of symptoms increased (table 2). There were some differences in the pattern of symptoms. Breathing problems and extreme tiredness or fatigue did not vary, but changes in mood, extreme tiredness or fatigue, hair loss, muscle weakness or joint stiffness, problems with mental abilities, sleep problems and symptoms of post-traumatic stress disorder were all more prevalent in those reporting after a longer interval. By contrast, symptoms of cough and loss of taste or smell were more prevalent in

Table 1 Demographics of all survey participants and (A) those who were not hospitalised and (B) those who were hospitalised

	All, n=3290	Not hospitalised, n=2873	Hospitalised, n=417	P value
Gender				
Female	2565 (78.0)	2269 (79.0)	296 (71.0)	<0.001
Male	686 (20.9)	568 (19.8)	118 (28.3)	
Age (years)				
17 or under	6 (0.2)	4 (0.1)	2 (0.5)	
18–24	55 (1.7)	51 (1.8)	4 (1.0)	
24–34	407 (12.4)	373 (13.0)	34 (8.2)	
35–44	778 (23.6)	702 (24.4)	76 (18.2)	<0.001
45–54	1117 (34.0)	988 (34.4)	129 (31.0)	
55–64	693 (21.1)	571 (19.9)	122 (29.3)	
65–74	193 (5.9)	153 (5.3)	40 (9.6)	
75 or older	40 (1.2)	30 (1.0)	10 (2.4)	
Ethnicity				
White	3031 (92.1)	2684 (93.4)	379 (91.0)	
Black, African, black British or Caribbean	41 (1.2)	31 (1.1)	10 (2.4)	0.07
Asian or Asian British	91 (2.8)	77 (2.7)	15 (3.6)	
Mixed or multiple ethnic groups	56 (1.7)	49 (1.7)	7 (1.7)	
Nation				
England	2742 (83.3)	2408 (83.8)	330 (79.1)	
Scotland	271 (8.2)	226 (7.9)	43 (10.3)	0.609
Wales	155 (4.7)	134 (4.7)	21 (5.0)	
Northern Ireland	43 (1.3)	30 (1.0)	13 (3.1)	
Current work status				
Working full time	1104 (33.6)	989 (34.4)	111 (26.6)	
Working part time	532 (16.2)	483 (16.8)	50 (12.0)	
Student	48 (1.5)	40 (1.4)	8 (1.9)	0.003
Retired	304 (9.2)	242 (8.4)	63 (15.1)	
Not working because of COVID-19	889 (27.0)	744 (25.9)	138 (33.1)	
Not working for other reasons	267 (8.1)	238 (8.3)	31 (7.4)	
Total household income				
Below £20 000	550 (16.7)	458 (15.9)	93 (22.3)	
£20 000–£30 000	556 (16.9)	487 (17.0)	69 (16.5)	
£30 001–£40 000	510 (15.5)	341 (11.9)	65 (15.6)	<0.001
£40 001–£70 000	796 (24.2)	700 (24.4)	95 (22.8)	
Over £70 000	496 (15.1)	448 (15.6)	45 (10.8)	
Pre-existing health condition				
Anxiety	390 (11.9)	335 (11.7)	55 (13.2)	0.37
Asthma	866 (26.3)	723 (25.2)	143 (34.3)	<0.001
Bronchiectasis	32 (1.0)	22 (0.8)	10 (2.4)	<0.001
Cancer	32 (1.0)	28 (1.0)	4 (1.0)	0.98
CVD	58 (1.8)	42 (1.5)	16 (3.8)	0.001
CKD	16 (0.5)	11 (0.4)	5 (1.2)	0.025
COPD	58 (1.6)	43 (1.5)	14 (3.4)	0.01

Continued



Table 1 Continued

	All, n=3290	Not hospitalised, n=2873	Hospitalised, n=417	P value
Depression	287 (8.7)	240 (8.4)	47 (11.3)	0.05
Diabetes	71 (2.2)	50 (1.7)	21 (5.0)	<0.001
HTN	255 (7.8)	202 (7.0)	53 (12.7)	<0.001
ILD	2 (0.1)	2 (0.1)	0 (0.0)	0.59
Obesity	218 (6.6)	173 (6.0)	45 (10.8)	<0.001

Data are presented as n (%). Statistical tests compare hospitalised and not hospitalised groups. P values are for χ^2 or t test as appropriate. Where numbers do not total 100%, missing values are due to questions unanswered by participants.

CKD, chronic kidney disease; COPD, chronic pulmonary disease; CVD, cardiovascular disease; HTN, hypertension; ILD, interstitial lung disease.

the earlier stages after the acute illness. More coexisting symptoms were reported in those reporting longer after their initial illness.

In the 417 respondents who reported being hospitalised with COVID-19, 57.1% were in hospital for less than 1 week, while 17% were in for more than 2 weeks (online supplemental table E2). As expected, pre-existing medical conditions were more prevalent in people who had required hospital care. Among hospitalised patients, 33.6% reported not needing any sort of respiratory support during the acute phase of their illness, 50.4% required non-invasive support with their breathing (eg, supplemental oxygen, and continuous positive airways pressure (CPAP)) and 10.6% had required endotracheal intubation. Those who had required intubation were no more likely to report ongoing breathing difficulties than those who had not (86.4% vs 92.6%; $p=0.485$). Of note, only 7% reported receiving a rehabilitation plan on discharge from hospital.

27.4% of all respondents reported that they had not spoken to their general practitioner (GP) or nurse, and only 27.9% reported being given information about things that they could do to aid their recovery. The quality of communication and information received (scored on

a scale of 0–10) was rated more highly in the hospitalised group in terms of clarity, usefulness, timeliness and empathy compared with those who had remained at home (online supplemental table E2).

In terms of importance (rated out 0–10), advice from healthcare professionals on managing difficulties after COVID-19 scored highest numerically (9.0); general information on difficulties after COVID-19 (8.9); the latest medical research on difficulties after COVID-19 (8.9); and reading about and talking to other people who have difficulties after COVID-19 (8.4) were all rated highly (online supplemental file 2).

Thematic analysis

Three key themes were identified from survey responses: (1) experience of living with COVID-19 – physical and psychological symptoms that fluctuate unpredictably; (2) interactions with healthcare; and (3) implications for the future – their own condition, society and the healthcare system and the need for research (figure 3). The characteristics of individuals quoted are given in online supplemental file 2.

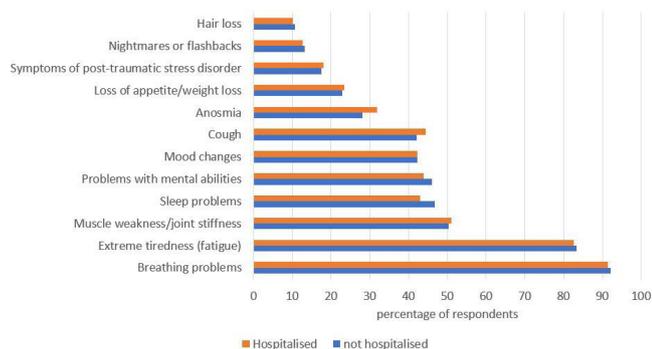


Figure 1 Frequency of symptoms reported by post-COVID-19 survey respondents graph showing percentages of individuals with long COVID reporting each symptom. Orange bar: people hospitalised during their acute COVID-19 illness (n=417); blue bar; not hospitalised (n=2873).

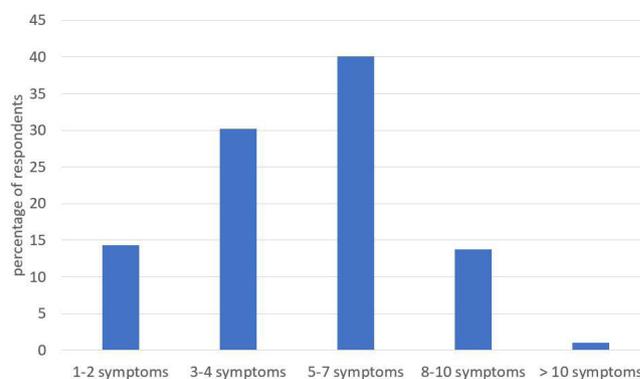


Figure 2 Number of symptoms reported by post-COVID-19 survey respondents. Respondents reported a mean (SD) of 5.0 (2.3) symptoms.

Table 2 Symptoms reported in those who report: (A) <4 weeks since symptom onset; (B) 4–8 weeks since symptoms onset; (C) 8–12 weeks since symptoms onset; (D) >12 weeks since symptoms onset

	<4 weeks, n=270	4–8 weeks, n=494	8–12 weeks, n=641	>12 weeks, n=1865	P value
Gender					
Female	214 (79.3)	387 (78.3)	506 (78.9)	1440 (77.2)	0.714
Male	52 (19.3)	98 (19.8)	131 (20.4)	403 (21.6)	
Age (years)					
17 or under	0 (0.0)	1 (0.2)	1 (0.2)	4 (0.2)	
18–24	9 (3.3)	8 (1.6)	8 (1.2)	30 (1.6)	
24–34	40 (14.8)	65 (13.2)	82 (12.8)	220 (11.8)	
35–44	64 (23.7)	123 (24.9)	159 (24.8)	427 (22.9)	0.038
45–54	91 (33.7)	168 (34.0)	222 (34.6)	630 (33.8)	
55–64	51 (18.9)	96 (19.4)	137 (21.4)	402 (21.6)	
65–74	13 (4.8)	22 (4.5)	28 (4.4)	128 (6.9)	
75 or older	2 (0.7)	10 (2.0)	4 (0.6)	24 (1.3)	
Ethnicity					
White	242 (89.6)	457 (92.5)	609 (95.0)	1735 (93.0)	
Black, African, black British or Caribbean	5 (1.9)	7 (1.4)	6 (0.9)	23 (1.2)	
Asian or Asian British	15 (5.6)	17 (3.4)	12 (1.9)	48 (2.6)	0.089
Mixed or multiple ethnic groups	3 (1.1)	7 (1.4)	10 (1.6)	36 (1.9)	
Symptoms					
Breathing problems	246 (91.1)	460 (93.1)	596 (93.0)	1707 (91.5)	0.47
Changes in mood, or anxiety or depression	93 (34.4)	206 (41.7)	266 (41.5)	842 (45.1)	0.006
Cough	135 (50.0)	221 (44.7)	275 (42.9)	752 (40.3)	0.013
Extreme tiredness/fatigue/lack of energy	216 (80.0)	406 (82.2)	535 (83.5)	1568 (84.1)	0.338
Hair loss	10 (3.7)	24 (4.9)	61 (9.5)	248 (13.3)	<0.001
Loss of appetite or weight loss	70 (25.9)	126 (25.5)	126 (19.7)	430 (23.1)	0.069
Loss of taste or smell (anosmia)	120 (44.4)	152 (30.8)	172 (26.8)	488 (26.2)	<0.001
Muscle weakness or joint stiffness	118 (43.7)	235 (47.6)	315 (49.1)	984 (52.8)	0.012
Nightmares or flashbacks	25 (9.3)	60 (12.1)	69 (10.8)	273 (14.6)	0.012
Problems with mental abilities including anxiety/depression	79 (29.3)	192 (38.9)	279 (43.5)	950 (50.9)	<0.001
Sleep problems	112 (41.5)	233 (47.2)	296 (46.2)	887 (47.6)	0.196
Symptoms of PTSD	35 (13.0)	74 (15.0)	111 (17.3)	352 (18.9)	0.037
Number of coexisting symptoms	4.7±2.1	4.8±2.3	4.8±2.3	5.1±2.4	0.005
Treatment during acute phase of virus					
Self-treatment at home	229 (84.8)	404 (81.8)	575 (89.7)	1652 (88.6)	<0.001
Hospitalised (but not intensive care)	32 (11.9)	68 (13.8)	52 (8.1)	160 (8.6)	
Hospitalised (intensive care)	9 (3.3)	22 (4.5)	14 (2.2)	53 (2.8)	

Data are presented as n (%) or mean (SD). P values of <0.05 are for χ^2 or one-way analysis of variance as appropriate. Where numbers do not total 100%, missing values are due to questions unanswered by participant. Changes of mood are taken to indicate a negative change in mood (ie, more anxious, more depressed, etc). PTSD, post-traumatic stress disorder.

Experience of living with COVID-19

Typically, respondents described multiple, often disabling symptoms causing major disruption to daily life and functioning. Both physical and psychological symptoms were common, frequently overlapping and often exacerbated

one another. Frustratingly for many, the ongoing disease course was non-linear, with recurrent and unpredictable symptomatic relapses. Participants highlighted the need to understand the long-lasting consequences of COVID-19, not just the immediate risk of death. Many individuals

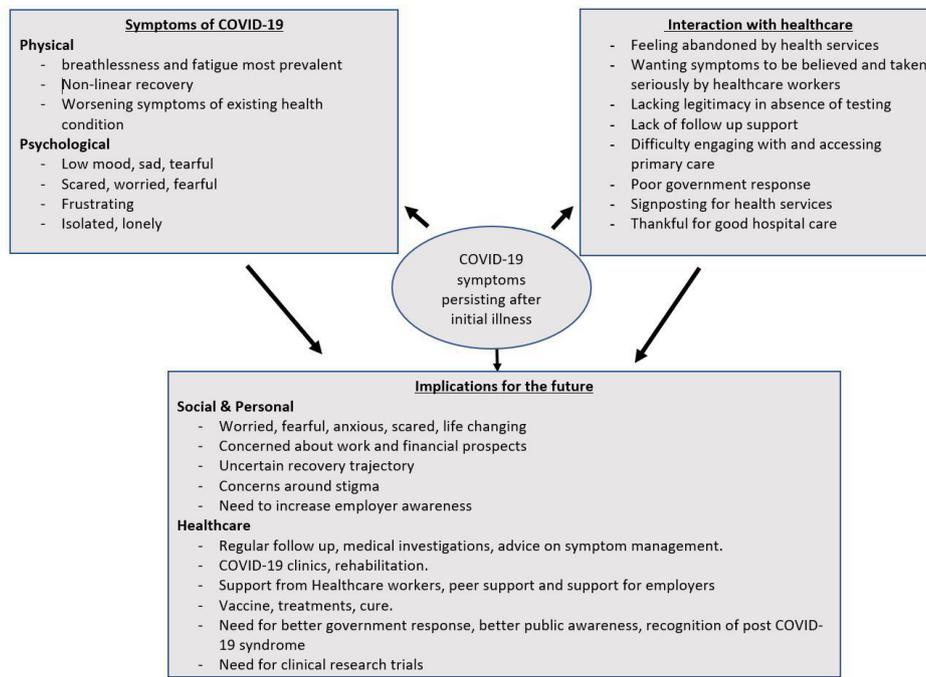


Figure 3 Thematic analysis of long COVID experience.

reported continuing to suffer with a range of physical symptoms, the most common being breathlessness and fatigue, which mirrors our quantitative findings.

Breathing is difficult on minor exertion, unable to walk upstairs without becoming short of breath, moderate exertion (walking up 4 or 5 floors) leads to a period of extreme breathlessness and exhaustion, unable to walk further.

Constant fatigue is a real problem.

Returning to normal life was almost impossible for some. Often even basic daily activities were limited, in

people who prior to getting ill had seen themselves as healthy (figure 4).

I just feel tired weak and sore all over. I lack the same energy I had to go about my daily life.

I tested positive over 4 weeks ago, normally fit and healthy, now I get breathlessness really quickly. Even just walking around the house, or washing the dishes, triggers it.

Many described their disease course as cyclical, with fluctuating symptoms and ‘false recoveries’ (figure 4).

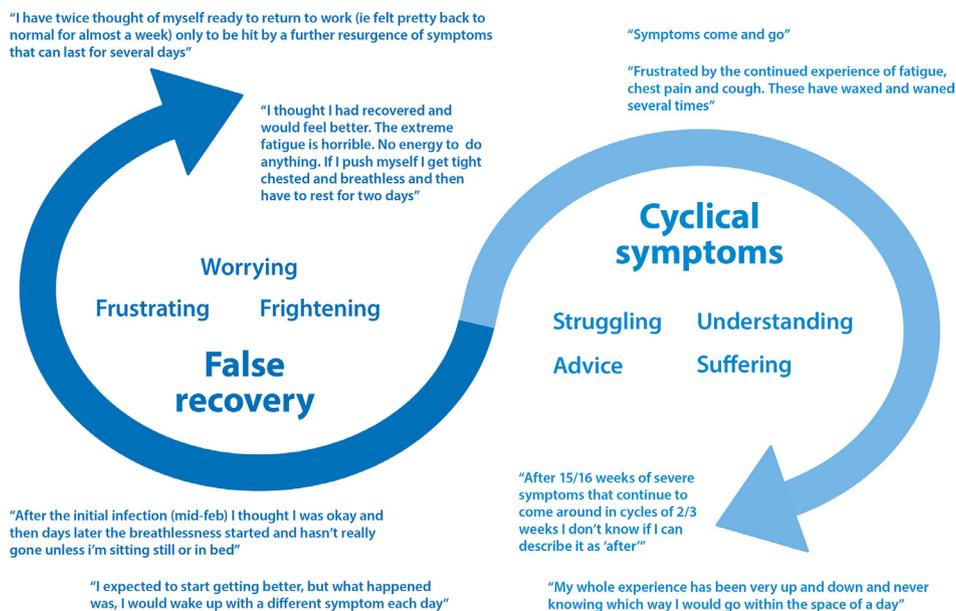


Figure 4 Infographic demonstrating the recovery/cyclical nature of long COVID symptoms from the respondent perspective.

I feel like I'm on the mend and then have a massive set back. It is very depressing. I was doing better for the last 6 weeks, then recently had a relapse where my breathlessness is back, and my fatigue is back. Very frustrating! One step forward and three steps back.

Uncertainty regarding the duration of symptoms, and completeness of recovery, was a major source of distress and was compounded by the general lack, and ambiguity, of information from healthcare providers regarding their condition (figure 4).

Understanding what is causing breathing difficulties, for example, scarring or inflammation, and evidence on how long these symptoms are likely to last. And evidence that a full recovery is likely.

Psychological problems were pronounced with around half (43.1%) reporting persistent and debilitating anxiety. Psychological distress had multiple origins, including physical symptoms, relapsing disease course and barriers to care.

I have noticed my anxiety has increased a lot. I know it's post-COVID symptoms but sometimes I doubt myself and think there is something else? it's very worrying however; I can manage my symptoms but it's more anxiety that creates more issues!

'Scared' and 'fearful' were repeatedly used to describe emotional status both in terms of respondents' current position and their expectations for the future. Others described feeling lonely or isolated and low mood was common.

Frightening, confusing, lonely, lacking support, worried to tell people in case they don't believe me or think I'm infectious, frustrating... it's hard sometimes not to feel bleak due to not knowing what the long term implications are, what will happen if I get it again, are any [of] my organs damaged and going to fail in the future.

Interactions with healthcare

Among comments about accessing care, perceptions and experiences were largely dichotomised between those who felt well supported and those who did not. Thus, many participants described feeling let down or abandoned by healthcare services, consistent with almost a third (27.4%) having not spoken to a GP or nurse about their difficulties.

I feel very deserted and alone by health care professionals.

Many participants described themselves as the forgotten patients of COVID-19. This cohort had experienced mild to severe symptoms but remained at home and were unable to be tested due to the lack of available tests.

Frustrating! No access to tests, swab and antibody, 'til way too late, resulting in negative outcome. GP's refusing to refer me to specialists, insisting I was 'fine' when clearly not - unable to breathe/speak. Only got referral by keep pushing GP, very tiring.... Went to local A&E by ambulance in late June, as severe breathing problems and chest pain, 111 thought I might be having heart attack. Docs v dismissive and felt I was wasting their time. Charming!

Experiences with the NHS 111 helpline and interacting with their GP could be negative; many felt that their primary care providers did not believe that they had long COVID symptoms and suggested their symptoms were due to stress/anxiety.

At the height of the illness in mid-March I fully expected to die. There was zero medical help, I was told to lock myself in my room and cope the best I can while struggling to breathe or move. My GP referred all COVID calls to NHS111, NHS111 took hours and if I hadn't got through to a knowing doctor by the time I was coughing up blood, who prescribed me strong antibiotics, if COVID hadn't got me, pneumonia would have done.

The feeling that their healthcare providers did not believe them or dismissed symptoms as being due to anxiety was frustrating.

[we need] Follow up for prolonged symptoms and clear self-help guidelines. To not be told it is anxiety and made to feel like it's not real.

Not feeling believed by healthcare professionals was a strong theme throughout, and participants felt their symptoms were being unfairly questioned. One individual described his experience as being '*gaslighted*' by his GP.

It has been an awful time and it made it worse, when I felt that I wasn't being believed about the symptoms. I didn't think I'd still be ill 8 months later. I feel there is very little support and my GP has ignored my symptoms. He has put it down to anxiety disorder. Which is so unfair. I know my body, and never have I experienced a burning sensation in my chest and breathing problems before.

By contrast, the respondents who reported feeling well supported were largely those who had been admitted to hospital and had laboratory confirmation of COVID-19 in the acute stages of their illness. This was even more marked for those who had been admitted to an HDU/ICU, who described the care and support they received in a very positive light.

I've been quite happy with the treatment I've received in my local hospital it's been reassuring Breathing Space keeping in touch.



Implications for the future

A third theme centred on individuals' future prospects and uncertainty regarding their symptoms, disease course and hopes for recovery to normal work and social life; future societal and healthcare professional understanding of their illness and structures of care, and the need for research and better treatments. Participants described their experience with COVID-19 as 'life-changing' with implications for many aspects of their life. The ongoing daily battle or 'fight' was repeatedly described as exhausting, with individuals despairing about their prospects in the future. Responses frequently addressed concerns related to their symptoms and employment situation. Many had not been able to return to their full duties at work, while others had not been able to return to work at all.

Can't go back to work as I still feel so unwell and my work (I am a teacher) are trying to push me into going back as I'm out of the 14-day infectious period and they are short staffed.

This caused significant financial stress, especially in the absence of a firm diagnosis to allow them to be signed off work or any certainty as to when things may get better. Increased need for extra help and care since contracting the virus was common. For many, this came from family members causing extra stress on loved ones and their relationships. For those requiring paid external care, the lack of funding available for this was noted.

I feel there is not much help for survivors in terms of emotional and financial support. One is left to figure out how best to manage on their own... because you do not have the financial support especially as a single parent you have to force and drag yourself to work in order to pay bills. Instead of concentrating on the healing process you are left with no choice but to work.

Participants expressed their hopes for the future in terms of increasing knowledge and awareness as well as access to further support interventions. This was needed especially for those who had not been admitted to hospital but were still experiencing longer lasting symptoms of the virus. In this context, more medical investigations including chest X-rays, blood test analysis and antibody testing were requested to identify and confirm disease status.

I would really like a thorough examination, (chest x-ray for example) to determine precisely what the problems are and how best they can be resolved. More access to medical checks for reassurance and an antibody test as my case was unconfirmed due to lack of testing at the time.

Others considered the availability of long COVID clinics to be of great value in providing ongoing support, advice and treatment for recovery from the virus.

Clinics set up with multi-disciplinary teams to address all aspects of recovery would be the best way forward for us all.

As well as a desire for recovery and return to 'normal life', there was also a need for more practical advice of how persistent symptoms could be managed. Suggestions such as increased rehabilitation services, breathing control exercises and energy conservation or pacing strategies were frequently mentioned, implying participants were anticipating or had experienced a very slow or incomplete recovery.

A programme of exercises starting from very simple movements and building up to more strenuous that can be used to rebuild strength & stamina gradually as fatigue & general malaise allow, taking into consideration the frequent relapses I have experienced every time I begin to improve a little! More information on how to cope with breathlessness. Techniques of breathing to help symptoms.

Hopes for future research into the longer term effects of COVID-19 were repeatedly mentioned in relation to vaccination, new treatments and a cure but also more generally to increase the knowledge base and understanding of the public, National Health Service (NHS) and government.

That there is government advice for people with long COVID. Recognition, guidance and support is not there.

There needs to be more information and research looking into individuals experiencing prolonged mild/moderate (ie, more than 4 weeks) symptoms during recovery for COVID.

DISCUSSION

People living with long COVID experience multiple, varying physical and psychological symptoms that are not necessarily related to initial illness severity or pre-existing health conditions. Interactions with healthcare are often unsatisfactory in terms of both the treatment that is available and the perceived legitimacy of their condition. This is accompanied by uncertainty about the future. Barriers to accessing healthcare and follow-up support exist and are experienced especially by people who managed the acute phase of their illness at home and did not have laboratory confirmation of COVID-19. This is the first study to investigate both symptoms and patient experience post-COVID-19, in a large cohort using both quantitative and qualitative methods.

Significance of findings

Long COVID is thought to affect approximately 10% of people who develop COVID-19,¹⁶ although estimates vary widely.^{20,21} Our findings demonstrate the varying patterns and persistence of symptoms of long COVID, which do not necessarily appear to be associated with severity of

the acute phase of the virus and are in keeping with those presented by other recent papers.^{8–13} The most common symptoms reported in this study of people with long COVID were breathing problems and fatigue. A European study of 2113 people recruited online, also found that fatigue and dyspnoea were the most prevalent symptoms postacute COVID-19 with a median of six symptoms per person persisting.²² We found that rates of reporting post-COVID-19 breathing problems differed by only a small amount between those who did or did not have pre-existing lung disease, consistent with a previous small study.¹³ Interestingly, the Zoe COVID-19 Symptom Study has identified asthma as the only pre-existing long-term condition associated with an increased risk of developing long COVID.

The variation in symptoms described supports the concept of long COVID comprising multiple different, often overlapping and coexisting syndromes.¹⁵ Having taken a mixed methods approach, our findings illustrate people's symptoms and how these impact on their lives, an understanding of which is vital in guideline and service development.²³ The themes that emerged from analysis of responses to this survey support those from a study, using interviews and focus groups to study lived experiences of long COVID in 114 participants,²⁴ which identified comparable themes including access to health-care services, concepts of improvements for the future and supported the need to establish quality principles for a long COVID service. Our work strengthens these findings, building the evidence base around the lived experience of long COVID in a larger cohort.

Many of our respondents reported difficulties when interacting with primary care services regarding their symptoms. Funding for long COVID services from NHS England was launched in November 2020.²⁵ However, access to these services requires referral from a general practitioner (GP), and participant responses highlight that a greater understanding of how long COVID can be recognised and distinguished from other possible causes of symptoms is needed. It is worth noting that provision of rehabilitation services was already inadequate prior to the pandemic.²⁶ Acknowledging the legitimacy of patient symptoms and diagnosis, especially in the absence of testing at the time of their initial illness, is important. NICE recently published best practice guidance on identifying and assessing those with symptoms post-COVID-19 and recommendations for management and follow-up.¹⁷ Further research efforts and initiatives are responding to the impact on individuals' lives caused by the pandemic²⁷ including an online portal established by the NHS for people with long-term symptoms (<https://www.yourcovidrecovery.nhs.uk/>).²⁸ Patient experience must be included in planning long COVID care, including the development of public understanding and perception, appropriate healthcare management strategies and research prioritisation.²⁹ Potential delivery of such services includes the use of novel virtual models^{30–32} and their role in supporting physical and cognitive recovery,³³

using multidisciplinary input to tackle a multitude of needs has been evaluated.³³ The HEAL-COVID study (<https://clinicaltrials.gov/ct2/show/NCT04801940>) also aims to identify and evaluate treatments that may be beneficial for people recovering from COVID-19. However, these studies focus only on patients who have been admitted to hospital, and thus far, similar studies have not been conducted in those patients who remained at home, but continue to experience ongoing symptoms.

Methodological issues

This is one of the largest studies to date exploring the lived experience of people with long COVID, and the inclusion of a large number of people who managed their acute illness at home provides important insight into this largely unseen group. Some limitations should be noted. The survey was completed by people who considered themselves to have long COVID and had chosen to visit an online site about the condition. As such, it contains important information about patient experience, but as a self-selecting population, the data cannot be used to make inferences about the experience or epidemiology of everyone who develops COVID-19. Furthermore, none of the reported symptoms or pre-existing health conditions were validated with an outcome measure or confirmed diagnosis, but rather were based only on subjective questioning.

Although a large sample, it is unclear how representative it is of all people with long COVID, as our sample has high proportions of women and white people. However, emerging research suggests that females may be at an increased risk of developing long COVID.¹⁵ Although the prevalence of asthma was 26% in our cohort, this was similar to that seen in the ISARIC dataset: 21% for 16–49 year olds.³⁴ A degree of sampling bias towards those with higher levels of digital literacy and individuals with more severe ongoing symptoms may have occurred, as such individuals could plausibly be more likely to be seeking online sources of support such as through the post-COVID-19 hub.

CONCLUSION

The three themes we identified each require specific attention to improve the understanding and management of long COVID. (1) Symptoms: how to relieve and better understand them; (2) healthcare: how to make it accessible for all people experiencing persisting effects of COVID-19, not just those admitted to hospital, and in particular those who did not have a COVID-19 test at the time of their initial illness; (3) uncertainty: reducing this by communicating existing knowledge more effectively and undertaking research to improve understanding of mechanisms and prognosis.

The COVID-19 pandemic reaches far beyond the acute phase of the illness. People with long COVID have substantial unmet care needs, and although services are being developed to address these needs, many people

experience prohibitive barriers, including feeling that their condition is not being taken seriously by healthcare providers.

Contributors SB and KEJP carried out the quantitative analysis. SB, KEJP and PW conducted the thematic analysis. SB wrote the first draft to which all authors contributed. The survey was developed by AUK-BLF partnership (AF, AC, SW and BW). All authors have reviewed and approved the final version. The corresponding author attests that all listed authors meet authorship criteria and that no others meeting the criteria have been omitted. NSH is the guarantor.

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Patient consent for publication Consent obtained directly from patient(s)

Ethics approval Ethical approval was granted by the Imperial College Research Governance and Integrity Team (ICREC Ref: 20IC6625). All survey respondents consented to the use of their responses for analysis and publication.

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REFERENCES

- Pollard CA, Morran MP, Nestor-Kalinowski AL. The COVID-19 pandemic: a global health crisis. *Physiol Genomics* 2020;52:549–57.
- Philip K, Cumella A, Farrington-Douglas J, et al. Respiratory patient experience of measures to reduce risk of COVID-19: findings from a descriptive cross-sectional UK wide survey. *BMJ Open* 2020;10:e040951.
- Philip KEJ, Lonergan B, Cumella A, et al. COVID-19 related concerns of people with long-term respiratory conditions: a qualitative study. *BMC Pulm Med* 2020;20:319.
- Struyf T, Deeks JJ, Dinnes J, et al. Signs and symptoms to determine if a patient presenting in primary care or hospital outpatient settings has COVID-19 disease. *Cochrane Database Syst Rev* 2020;7:CD013665.
- Wu Z, McGoogan JM. Characteristics of and Important Lessons From the Coronavirus Disease 2019 (COVID-19) Outbreak in China: Summary of a Report of 72 314 Cases From the Chinese Center for Disease Control and Prevention. *JAMA* 2020;323:1239–42.
- Hopkinson NS, Rossi N, El-Sayed Moustafa J, et al. Current smoking and COVID-19 risk: results from a population symptom APP in over 2.4 million people. *Thorax* 2021;76:714–22.
- Menni C, Valdes AM, Freidin MB, et al. Real-time tracking of self-reported symptoms to predict potential COVID-19. *Nat Med* 2020;26:1037–40.
- Hopkinson NS, Jenkins G, Hart N. COVID-19 and what comes after? *Thorax* 2021;76:324–5.
- Hall J, Myall K, Lam JL, et al. Identifying patients at risk of post-discharge complications related to COVID-19 infection. *Thorax* 2021;76:408–11.
- Mandal S, Barnett J, Brill SE, et al. 'Long-COVID': a cross-sectional study of persisting symptoms, biomarker and imaging abnormalities following hospitalisation for COVID-19. *Thorax* 2021;76:396–8.
- Arnold DT, Hamilton FW, Milne A, et al. Patient outcomes after hospitalisation with COVID-19 and implications for follow-up: results from a prospective UK cohort. *Thorax* 2021;76:399–401.
- Shah AS, Wong AW, Hague CJ, et al. A prospective study of 12-week respiratory outcomes in COVID-19-related hospitalisations. *Thorax* 2021;76:402–4.
- Townsend L, Dowds J, O'Brien K, et al. Persistent poor health after COVID-19 is not associated with respiratory complications or initial disease severity. *Ann Am Thorac Soc* 2021;18:997–1003.
- Stavem K, Ghanima W, Olsen MK, et al. Persistent symptoms 1.5-6 months after COVID-19 in non-hospitalised subjects: a population-based cohort study. *Thorax* 2021;76:405–7.
- NIHR Themed Review: Living with Covid19 - Second review 2021.
- Sivan M, Taylor S. Nice guideline on long covid. *BMJ* 2020;371:m4938.
- NICE. *COVID-19 rapid guideline: managing the long-term effects of COVID-19*. NG188, 2020.
- Greenhalgh T, Knight M, A'Court C, et al. Management of post-acute covid-19 in primary care. *BMJ* 2020;370:m3026.
- Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3:77–101.
- Lopez-Leon S, Wegman-Ostrosky T, Perelman C, et al. More than 50 long-term effects of COVID-19: a systematic review and meta-analysis. *medRxiv* 2021:2021.01.27.21250617.
- Walker AJ, MacKenna B, Inglesby P, et al. Clinical coding of long COVID in English primary care: a federated analysis of 58 million patient records *in situ* using OpenSAFELY. *Br J Gen Pract* 2021:2021.2005.2006.21256755.
- Goërtz YMJ, Van Herck M, Delbressine JM, et al. Persistent symptoms 3 months after a SARS-CoV-2 infection: the post-COVID-19 syndrome? *ERJ Open Res* 2020;6:00542-2020-2020.
- Gorna R, MacDermott N, Rayner C, et al. Long COVID guidelines need to reflect lived experience. *Lancet* 2021;397:455–7.
- Ladds E, Rushforth A, Wieringa S, et al. Persistent symptoms after Covid-19: qualitative study of 114 "long Covid" patients and draft quality principles for services. *BMC Health Serv Res* 2020;20:1144.
- Rockfield S, Chhabra R, Robertson M, et al. Links between iron and lipids: implications in some major human diseases. *Pharmaceuticals* 2018;11:113.
- Philip K, Gaduzo S, Rogers J, et al. Patient experience of COPD care: outcomes from the British lung Foundation patient Passport. *BMJ Open Respir Res* 2019;6:e000478.
- Perlis RH, Haneuse SJPA, Rubenfeld GD, et al. Reporting clinical studies affected by the COVID-19 pandemic: guidelines for authors. *JAMA Netw Open* 2021;4:e2036155.
- Mahase E. Covid-19: What do we know about "long covid"? *BMJ* 2020;370:m2815.
- Callard F, Perego E. How and why patients made long Covid. *Soc Sci Med* 2021;268:113426.
- Barker-Davies RM, O'Sullivan O, Senaratne KPP, et al. The Stanford Hall consensus statement for post-COVID-19 rehabilitation. *Br J Sports Med* 2020;54:949–59.
- Wise J. Long covid: who calls on countries to offer patients more rehabilitation. *BMJ* 2021;372:n405.
- Polgar O, Aljishi M, Barker RE, et al. Digital habits of PR service-users: implications for home-based interventions during the COVID-19 pandemic. *Chron Respir Dis* 2020;17:1479973120936685.
- Puchner B, Sahanic S, Kirchmair R, et al. Beneficial effects of multi-disciplinary rehabilitation in postacute COVID-19: an observational cohort study. *Eur J Phys Rehabil Med* 2021;57:189–98.
- Bloom CI, Drake TM, Docherty AB, et al. Risk of adverse outcomes in patients with underlying respiratory conditions admitted to hospital with COVID-19: a national, multicentre prospective cohort study using the ISARIC who clinical characterisation protocol UK. *Lancet Respir Med* 2021;9:699–711.

Supplementary file 1; Summary table and bubble chart from thematic analysis of survey responses

Word	Length	Count	Weighted Percentage	Similar Words
feel	4	2063	1.54%	feel, feeling, feelings, feels
covids	6	1809	1.35%	'covid, covid, covid', covids
symptoms	8	1757	1.31%	symptom, symptoms, symptoms'
getting	7	1508	1.13%	'get, get, gets, getting
weeks	5	1314	0.98%	week, weekly, weeks
helps	5	1199	0.90%	help, help', helped, helpful, helping, helps
likely	6	1181	0.88%	like, liked, likely, likes
breaths	7	1161	0.87%	breath, breathe, breathe', breathed, breathes, breathing, breaths
tests	5	1105	0.83%	test, tested, testing, tests
times	5	1023	0.76%	time, time', timely, times
know	4	1014	0.76%	know, knowing, knows
still	5	1008	0.75%	still
days	4	978	0.73%	'day, day, day', days
long	4	975	0.73%	'long, long, longed
support	7	938	0.70%	support, supported, supporters, supporting, supportive
working	7	937	0.70%	work, worked, working, works
now	3	890	0.67%	now
chest	5	783	0.59%	chest, chested, chests
people	6	739	0.55%	people, people', peoples
just	4	733	0.55%	'just, just
back	4	720	0.54%	back, back', backs
needs	5	638	0.48%	need, needed, needing, needs
illnesses	9	633	0.47%	ill, illness, illnesses
better	6	603	0.45%	better, better', better'
pains	5	592	0.44%	pain, painful, pains
informing	9	588	0.44%	inform, informant, information, informative, informed, informing, informs
hospitals	9	558	0.42%	hospital, hospitalization, hospitalized, hospitals
lungs	5	552	0.41%	lung, lungs
months	6	544	0.41%	month, monthly, months, months'
posting	7	502	0.38%	post, posted, posting
recovery	8	499	0.37%	'recovery', recoveries, recovery, recovery'
one	3	483	0.36%	one, ones

Supplementary file 1; Summary table and bubble chart from thematic analysis of survey responses

also	4	464	0.35%	also
breathlessness	14	462	0.35%	breathless, breathlessness
doctor	6	460	0.34%	doctor, doctors
take	4	457	0.34%	take, takes, taking
worrying	8	457	0.34%	worried, worries, worry, worrying, worryingly
fatigue	7	455	0.34%	fatigue, fatigue', fatigued, fatigues
normally	8	455	0.34%	'normal, 'normal', normal, normality, normally
medics	6	453	0.34%	medic, medical, medically, medicate, medicated, medicating, medication, medications, medics
advice	6	443	0.33%	advice, advices
health	6	442	0.33%	health
going	5	442	0.33%	going, going'
think	5	436	0.33%	think, thinking, thinks
recovering	10	429	0.32%	'recovered', recover, recovered, recovering, recovers
understanding	13	428	0.32%	understand, understandable, understandably, understanding, understands
life	4	427	0.32%	life, life'
even	4	421	0.31%	even, evening, evenings
really	6	412	0.31%	really
never	5	409	0.31%	never
able	4	406	0.30%	able
much	4	404	0.30%	much
coughs	6	400	0.30%	'cough, cough, coughed, coughing, coughs
frustrating	11	395	0.30%	frustrated, frustrating, frustratingly, frustration, frustrations
homes	5	389	0.29%	home, homes
virus	5	380	0.28%	virus, viruses
felt	4	379	0.28%	felt
follow	6	374	0.28%	follow, followed, follower, following, follows
walk	4	373	0.28%	walk, walked, walking, walks
asthma	6	370	0.28%	asthma, asthma'
exercising	10	362	0.27%	exercise, exercised, exerciser, exercises, exercising
problems	8	357	0.27%	problem, problems
terms	5	355	0.27%	term, terms

Supplementary file 1; Summary table and bubble chart from thematic analysis of survey responses

struggling	10	354	0.26%	struggle, struggled, struggles, struggling
suffering	9	352	0.26%	suffer, suffered, sufferer, sufferers, suffering, suffers
seem	4	345	0.26%	seem, seemed, seemingly, seems
want	4	340	0.25%	want, wanted, wanting, wants
caring	6	337	0.25%	care, cared, careful, cares, caring
seeing	6	331	0.25%	see, seeing
itâ	3	328	0.25%	itâ
experiences	11	320	0.24%	experience, experiences, experiences', experiment
trying	6	319	0.24%	'try, tried, try, tried, trying
told	4	309	0.23%	told
using	5	309	0.23%	use, used, useful, usefully, using
things	6	309	0.23%	thing, things
starts	6	308	0.23%	start, started, starting, starts
worse	5	304	0.23%	worse
activity	8	300	0.22%	activate, activation, active, actively, activities, activities', activity
make	4	297	0.22%	make, makes, making
left	4	292	0.22%	left
anxiety	7	291	0.22%	anxiety, anxiety'
since	5	289	0.22%	since
issues	6	284	0.21%	issue, issued, issues
frightening	11	284	0.21%	frightened, frightening, frightens
effects	7	283	0.21%	effect, effected, effecting, effective, effectively, effectiveness, effects
last	4	280	0.21%	last, lasted, lasting, lastly, lasts
return	6	279	0.21%	return, returned, returning, returns
calls	5	274	0.20%	call, called, calling, calls
experiencing	12	271	0.20%	experienced, experiencing
lot	3	268	0.20%	lot, lots
exhaustion	10	268	0.20%	exhaust, exhausted, exhausting, exhaustion, exhausts
donâ	4	264	0.20%	donâ
manage	6	260	0.19%	manage, managed, management, manager, managers, managing
improve	7	256	0.19%	improve, improved,

Supplementary file 1; Summary table and bubble chart from thematic analysis of survey responses

				improvement, improvements, improves, improving
difficult	9	254	0.19%	difficult
checks	6	254	0.19%	check, checked, checking, checks
blood	5	252	0.19%	blood, blooded, bloods
find	4	249	0.19%	find, finding, findings, finds
well	4	249	0.19%	well, well', wellness
thank	5	248	0.19%	thank, thankful, thankfully, thanks
fits	4	245	0.18%	fit, fitness, fits, fitting
due	3	245	0.18%	due
shortness	9	237	0.18%	short, shortly, shortness
antibody	8	237	0.18%	antibodies, antibody
isolation	9	237	0.18%	isolate, isolated, isolating, isolation
scary	5	236	0.18%	scary
coming	6	235	0.18%	'coming, come, comes, coming
physical	8	235	0.18%	physical, physically
severity	8	233	0.17%	sever, several, severe, severely, severity, severely
got	3	232	0.17%	got
anxious	7	232	0.17%	'anxious', anxious, anxious'
first	5	232	0.17%	first, firstly
lack	4	230	0.17%	lack, lacking
difficulties	12	230	0.17%	difficulties, difficulty
bad	3	228	0.17%	bad, badly
alone	5	227	0.17%	alone
hardly	6	224	0.17%	hard, hardly
nhs	3	224	0.17%	nhs
little	6	220	0.16%	little
ongoing	7	218	0.16%	ongoing
body	4	216	0.16%	bodies, body, bodys
good	4	215	0.16%	good, goodness, goods
anything	8	215	0.16%	anything
heart	5	214	0.16%	heart
many	4	214	0.16%	many
infections	10	213	0.16%	infect, infected, infection, infections, infective
may	3	209	0.16%	may
scares	6	208	0.16%	scare, scared, scares, scaring
without	7	208	0.16%	without
tiring	6	207	0.15%	tire, tired, tires, tiring

Supplementary file 1; Summary table and bubble chart from thematic analysis of survey responses

rests	5	206	0.15%	'rest', rest, rested, resting, rests
phoning	7	206	0.15%	phone, phoned, phones, phoning
treatments	10	205	0.15%	'treatment', treatment, treatments
patients	8	203	0.15%	patient, patients
fears	5	202	0.15%	fear, feared, fearful, fearfully, fearing, fears
extremely	9	200	0.15%	extreme, extremely
inhalers	8	199	0.15%	inhalation, inhalations, inhale, inhaler, inhalers, inhaling
damage	6	199	0.15%	damage, damage', damaged, damages, damaging
believe	7	197	0.15%	believe, believed, believer, believes, believing
professionals	13	196	0.15%	professional, professionals
mental	6	194	0.15%	mental, mentally
available	9	193	0.14%	avail, availability, available
unable	6	193	0.14%	unable
contact	7	190	0.14%	contact, contacted, contacting, contacts
thought	7	190	0.14%	thought, thoughts
continuous	10	190	0.14%	continual, continually, continuation, continue, continued, continues, continuing, continuity, continuous, continuously
mildly	6	190	0.14%	'mild', mild, mildly, mildly'
tightness	9	188	0.14%	tight, tightness
ends	4	188	0.14%	end, ended, ending, ends
positive	8	187	0.14%	position, positive, positive', positively
two	3	186	0.14%	two
happening	9	180	0.13%	happen, happened, happening, happens
concerns	8	179	0.13%	concern, concerned, concerning, concerns
living	6	178	0.13%	live, lived, lives, living
every	5	178	0.13%	'every, every
ray	3	176	0.13%	ray, rays
hoping	6	175	0.13%	hope, hoped, hopeful, hopefully, hoping
whether	7	174	0.13%	whether
clearly	7	172	0.13%	clear, cleared, clearing, clearly, clears
access	6	171	0.13%	access, accessed, accessible,

Supplementary file 1; Summary table and bubble chart from thematic analysis of survey responses

				accessing
changing	8	171	0.13%	change, changed, changes, changing
sleeping	8	169	0.13%	sleep, sleeping
differing	9	168	0.13%	differ, difference, differences, different, differently, differing
expecting	9	168	0.13%	'expect', expect, expectancy, expectation, expectations, expected, expecting, expects
research	8	168	0.13%	research, researched, researchers, researching
affects	7	167	0.12%	affect, affected, affecting, affection, affects
made	4	167	0.12%	made
given	5	166	0.12%	given
personally	10	165	0.12%	'personal, person, personal, personality, personalized, personally
enough	6	165	0.12%	enough
ever	4	163	0.12%	ever
others	6	163	0.12%	others
nursing	7	163	0.12%	nurse, nursed, nurses, nursing
group	5	163	0.12%	group, groups
canã	4	162	0.12%	canã
cause	5	161	0.12%	cause, caused, causes, causing
family	6	159	0.12%	families, family
later	5	159	0.12%	later
though	6	159	0.12%	though
negative	8	158	0.12%	negative, negatively, negatives, negativity
gps	3	158	0.12%	gps
unwell	6	158	0.12%	unwell, unwell'
year	4	157	0.12%	year, years
surely	6	156	0.12%	sure, surely
way	3	153	0.11%	way, ways
etc	3	153	0.11%	etc
facing	6	152	0.11%	face, faced, faces, facing
relapse	7	148	0.11%	relapse, relapsed, relapses, relapsing
full	4	147	0.11%	full, fullness
keeps	5	146	0.11%	keep, keeping, keeps
talk	4	146	0.11%	talk, talked, talking
looks	5	146	0.11%	'looked, look, looked, looking, looks
respiratory	11	146	0.11%	respiratory

Supplementary file 1; Summary table and bubble chart from thematic analysis of survey responses

cases	5	145	0.11%	case, cases
111	3	144	0.11%	111
hours	5	144	0.11%	hour, hourly, hours
seriously	9	144	0.11%	serious, seriously, seriousness
generally	9	144	0.11%	general, generally
asked	5	143	0.11%	ask, asked, asking, asks
depression	10	142	0.11%	depressant, depressants, depressed, depressing, depression, depressive
lonely	6	141	0.11%	lonely
new	3	140	0.10%	new
found	5	139	0.10%	found, founded
awareness	9	139	0.10%	'aware', aware, awareness
antibiotics	11	138	0.10%	antibiotic, antibiotics
constant	8	137	0.10%	constant, constantly
taken	5	137	0.10%	taken
completely	10	134	0.10%	complete, completed, completely, completing
appointment	11	134	0.10%	appointment, appointments
sickness	8	134	0.10%	sick, sickness
confusing	9	133	0.10%	confused, confusing, confusion
march	5	132	0.10%	march
initiative	10	131	0.10%	initial, initially, initiated, initiative
nothing	7	130	0.10%	nothing
someone	7	130	0.10%	someone
clinics	7	130	0.10%	clinic, clinical, clinically, clinics
answers	7	129	0.10%	answer, answered, answering, answers
employment	10	129	0.10%	employed, employer, employers, employment
done	4	129	0.10%	done
quite	5	128	0.10%	quit, quite
around	6	127	0.09%	around
levels	6	127	0.09%	level, levels
yet	3	126	0.09%	'yet', yet
waiting	7	126	0.09%	wait, waited, waiting
bed	3	126	0.09%	bed, bedding, beds
putting	7	126	0.09%	put, puts, putting
viral	5	125	0.09%	viral
possibly	8	125	0.09%	possibilities, possibility, possible, possibly
runs	4	123	0.09%	run, running, runs

Supplementary file 1; Summary table and bubble chart from thematic analysis of survey responses

energy	6	122	0.09%	energy
speak	5	121	0.09%	speak, speaking, speaks
went	4	121	0.09%	went
services	8	120	0.09%	'service', service, services
might	5	119	0.09%	might
dying	5	118	0.09%	die, died, dieing, dying
deal	4	117	0.09%	deal, dealing, deals
although	8	117	0.09%	although
especially	10	117	0.09%	especially
scan	4	116	0.09%	scan, scanned, scans
offered	7	116	0.09%	offer, offered, offering, offers
awful	5	116	0.09%	awful
didnâ	5	116	0.09%	didnâ
condition	9	115	0.09%	condition, conditioning, conditions
healthy	7	115	0.09%	healthy
giving	6	114	0.09%	give, gives, giving
self	4	114	0.09%	'self, self
nights	6	113	0.08%	night, nightly, nights
regular	7	113	0.08%	regular, regularly
governments	11	111	0.08%	gouvernement, government, governments
debilitating	12	111	0.08%	debilitated, debilitating, debilitation
early	5	110	0.08%	early
fevers	6	110	0.08%	fever, fevers
treating	8	109	0.08%	treat, treated, treating
right	5	109	0.08%	right, rightly, rights
coping	6	108	0.08%	cope, coped, coping
daily	5	108	0.08%	daily
longer	6	107	0.08%	longer
reassurance	11	106	0.08%	reassurance, reassure, reassured, reassuring
results	7	106	0.08%	result, resulted, resulting, results
become	6	106	0.08%	become, becomes, becoming
properly	8	106	0.08%	'proper', 'properly, proper, properly
stays	5	106	0.08%	'stay, stay, stayed, staying, stays
highly	6	105	0.08%	high, highly
leave	5	105	0.08%	leave, leaves, leaving
impact	6	104	0.08%	impact, impacted, impactful, impacting, impacts

Supplementary file 1; Summary table and bubble chart from thematic analysis of survey responses

relatives	9	104	0.08%	relate, related, relates, relating, relation, relative, relatively, relatives
listens	7	104	0.08%	listen, listened, listening, listens
sometimes	9	103	0.08%	sometime, sometimes
future	6	103	0.08%	future
gone	4	103	0.08%	gone
headaches	9	103	0.08%	headache, headaches
something	9	103	0.08%	something
husband	7	103	0.08%	husband, husbands
throat	6	103	0.08%	throat, throats
points	6	102	0.08%	point, pointed, points
away	4	101	0.08%	away
readings	8	101	0.08%	read, reading, readings
consultant	10	101	0.08%	consultant, consultants, consultation, consultations, consulted, consulting, consults
tell	4	101	0.08%	tell, telling, tells
actually	8	100	0.07%	actual, actually
however	7	100	0.07%	however
bit	3	99	0.07%	bit, bits
previously	10	99	0.07%	previous, previously
sent	4	98	0.07%	sent
referred	8	98	0.07%	refer, reference, referred, referring
aching	6	98	0.07%	ache, aches, aching
received	8	98	0.07%	receive, received, receiving
ideas	5	97	0.07%	idea, ideas
old	3	97	0.07%	old, olds
permanently	11	96	0.07%	permanantly, permanent, permanently
another	7	96	0.07%	another
fully	5	96	0.07%	fully
seen	4	96	0.07%	seen
worst	5	96	0.07%	worst
stop	4	96	0.07%	stop, stopped, stopping, stops
sore	4	95	0.07%	sore, sorely, soreness, sores
specialist	10	95	0.07%	specialist, specialists
terrifying	10	95	0.07%	terrified, terrifying, terrifying
slow	4	95	0.07%	slow, slowed, slowing, slows
increased	9	94	0.07%	increase, increased, increases, increasing, increasingly
diagnosing	10	93	0.07%	diagnosable, diagnose,

Supplementary file 1; Summary table and bubble chart from thematic analysis of survey responses

				diagnosed, diagnoses, diagnosing
friends	7	93	0.07%	friend, friends
steroids	8	93	0.07%	steroid, steroids
dismissive	10	92	0.07%	'dismissed', dismiss, dismissed, dismisses, dismissing, dismissive, dismissiveness
despite	7	92	0.07%	despite
surgery	7	91	0.07%	surgeries, surgery
covid19	7	91	0.07%	covid19
next	4	90	0.07%	next
greatly	7	90	0.07%	'great', great, greatly
currently	9	89	0.07%	current, currently
wonder	6	89	0.07%	wonder, wondered, wonderful, wondering
best	4	89	0.07%	best
far	3	89	0.07%	far
nearly	6	89	0.07%	near, nearly
publicity	9	89	0.07%	public, publication, publications, publicity, publicized
please	6	89	0.07%	please, pleased
pneumonia	9	88	0.07%	pneumonia
always	6	88	0.07%	'always, always
low	3	88	0.07%	low, lows
smell	5	87	0.07%	smell, smells
ago	3	87	0.07%	ago
almost	6	87	0.07%	almost
lost	4	87	0.07%	lost
took	4	87	0.07%	took
usually	7	87	0.07%	usual, usually
wish	4	86	0.06%	wish, wished, wishes, wishing
realising	9	85	0.06%	realisation, realise, realised, realising
attacks	7	85	0.06%	attack, attacked, attacks
job	3	84	0.06%	job, jobs
poorly	6	84	0.06%	poor, poorly
temperature	11	84	0.06%	temperature, temperatures
often	5	84	0.06%	often
came	4	84	0.06%	'came, came
practice	8	83	0.06%	practical, practically, practice, practices
period	6	83	0.06%	period, periodic, periods

Supplementary file 1; Summary table and bubble chart from thematic analysis of survey responses

hospitalised	12	83	0.06%	hospitalisation, hospitalised
plans	5	82	0.06%	plan, planned, planning, plans
totally	7	82	0.06%	total, totally
loss	4	81	0.06%	loss, lossing
oxygen	6	81	0.06%	oxygen
disease	7	80	0.06%	disease, diseases
guidance	8	80	0.06%	guidance, guidances
confirm	7	79	0.06%	confirm, confirmation, confirmed
lucky	5	79	0.06%	lucky
investigations	14	79	0.06%	investigate, investigated, investigating, investigation, investigations
developing	10	79	0.06%	develop, developed, developing, developments, develops
shows	5	78	0.06%	show, showed, showing, shows
online	6	77	0.06%	online
muscles	7	77	0.06%	'muscle', muscle, muscles
course	6	77	0.06%	course, courses
'fine'	6	76	0.06%	'fine', fine
acknowledgement	15	76	0.06%	acknowledge, acknowledged, acknowledgement, acknowledges, acknowledging, acknowledgment, acknowledgments
setting	7	76	0.06%	set, sets, setting, settings
diagnosis	9	76	0.06%	diagnosis
real	4	76	0.06%	real
discharge	9	75	0.06%	discharge, discharged
admitted	8	74	0.06%	admit, admits, admitted, admitting
healthcare	10	74	0.06%	healthcare, healthcarer
progress	8	73	0.05%	progress, progressed, progresses, progressing, progression, progressive, progressively
stressful	9	73	0.05%	stress, stressed, stressful, stressing
abandoned	9	73	0.05%	abandone, abandoned, abandonement, abandonment
info	4	72	0.05%	info
wasnâ	5	72	0.05%	wasnâ
weakness	8	72	0.05%	weak, weakness, weaknesses
catch	5	72	0.05%	catch, catches, catching

Supplementary file 1; Summary table and bubble chart from thematic analysis of survey responses

prescribing	11	71	0.05%	prescribe, prescribed, prescribes, prescribing
xray	4	71	0.05%	xray, xrays
less	4	71	0.05%	less
slightly	8	70	0.05%	slight, slightly
everything	10	70	0.05%	everything
media	5	70	0.05%	media
similar	7	69	0.05%	similar, similarly
else	4	69	0.05%	else
immunity	8	69	0.05%	immune, immunity
interested	10	69	0.05%	interest, interested, interesting
particularly	12	69	0.05%	particular, particularly
house	5	69	0.05%	house, houses
places	6	69	0.05%	place, placed, places
telephone	9	68	0.05%	telephone, telephoned
limiting	8	68	0.05%	limit, limitations, limited, limiting, limits
sharing	7	68	0.05%	share, shared, sharing
system	6	68	0.05%	system, systemically, systems
taste	5	68	0.05%	taste, tastes
advised	7	68	0.05%	advise, advised, advising
visit	5	68	0.05%	visit, visited, visiting, visits
everyone	8	67	0.05%	everyone
rather	6	67	0.05%	rather
three	5	67	0.05%	three
twice	5	67	0.05%	twice
whole	5	67	0.05%	whole
explain	7	67	0.05%	explain, explained, explaining
provide	7	66	0.05%	provide, provided, provider, providers, provides, providing
assessment	10	66	0.05%	assess, assessed, assessing, assessment, assessments
exertion	8	65	0.05%	exert, exerted, exerting, exertion, exertional, exertions
monitor	7	65	0.05%	monitor, monitored, monitoring
brain	5	64	0.05%	brain, brain'
eating	6	64	0.05%	eat, eating, eats
rate	4	64	0.05%	rate, rated
questions	9	64	0.05%	question, questioned, questioning, questions
terrible	8	64	0.05%	terrible, terribly
physio	6	63	0.05%	physio, physios

Supplementary file 1; Summary table and bubble chart from thematic analysis of survey responses

pressure	8	63	0.05%	pressure, pressured, pressures
became	6	63	0.05%	became
children	8	63	0.05%	children
parts	5	63	0.05%	part, parting, partly, parts
moment	6	63	0.05%	moment, moments
turn	4	63	0.05%	turn, turned, turning, turns
suggested	9	62	0.05%	suggest, suggested, suggesting, suggestion, suggestions, suggestive, suggests
knowledgeable	13	62	0.05%	knowledgable, knowledge, knowledgeable
already	7	62	0.05%	already
flu	3	62	0.05%	'flu, flu, flu'
website	7	61	0.05%	website, websites
whilst	6	61	0.05%	whilst
unknown	7	61	0.05%	unknown, unknowns
couple	6	61	0.05%	couple, coupled
stairs	6	61	0.05%	stair, stairs
heading	7	61	0.05%	head, head', headed, heading
joint	5	60	0.04%	joint, joints
quickly	7	60	0.04%	quick, quickly
reduced	7	60	0.04%	reduce, reduced, reducing
ambulance	9	60	0.04%	ambulance, ambulances
anyone	6	60	0.04%	anyone, anyones
known	5	60	0.04%	known
staff	5	59	0.04%	staff, staffs
rehabilitation	14	59	0.04%	rehabilitate, rehabilitated, rehabilitating, rehabilitation
dont	4	59	0.04%	dont
slowly	6	59	0.04%	slowly
recognised	10	59	0.04%	recognise, recognised, recognises, recognising, recognition
definitely	10	59	0.04%	definite, definitely, definition, definitive, definitely
including	9	58	0.04%	include, included, includes, including
april	5	58	0.04%	april
least	5	58	0.04%	least
appear	6	58	0.04%	appear, appearance, appeared, appearing, appears
pushing	7	58	0.04%	'push, push, pushed, pushing
function	8	58	0.04%	function, functional, functioning, functions

Supplementary file 1; Summary table and bubble chart from thematic analysis of survey responses

main	4	58	0.04%	main, mainly
havenâ	6	57	0.04%	havenâ
emotions	8	57	0.04%	emotion, emotional, emotionally, emotions
burning	7	57	0.04%	burn, burning, burns
waves	5	56	0.04%	wave, waves
regards	7	55	0.04%	regard, regarded, regarding, regards
easily	6	55	0.04%	easily
sense	5	55	0.04%	sense
locally	7	54	0.04%	local, locality, locally
cold	4	54	0.04%	cold, colds
ups	3	54	0.04%	up', upped, ups
tiredness	9	53	0.04%	tiredness
kind	4	53	0.04%	kind, kindly, kindness
means	5	53	0.04%	mean, meaning, means
discuss	7	53	0.04%	discuss, discussed, discussing, discussion, discussions
peak	4	53	0.04%	peak, peaked, peaking, peaks
wake	4	53	0.04%	wake, wakes, waking
beginning	9	52	0.04%	begin, beginning, beginning, beginnings
focus	5	52	0.04%	focus, focused, focuses, focusing
suddenly	8	52	0.04%	sudden, suddenly
swab	4	52	0.04%	swab, swabbed, swabs
team	4	52	0.04%	team, teamed, teams
grateful	8	52	0.04%	grateful
huge	4	51	0.04%	huge, hugely
lingering	9	51	0.04%	linger, lingered, lingering, lingers
control	7	51	0.04%	control, controlled, controlling
intensive	9	51	0.04%	intense, intensely, intensity, intensive
second	6	51	0.04%	second, secondly
moving	6	51	0.04%	move, moved, moves, moving
present	7	51	0.04%	present, presentation, presentations, presented, presenters, presenting, presently
let	3	51	0.04%	let, letting
finally	7	50	0.04%	'finally, final, finally
nightmare	9	50	0.04%	nightmare, nightmares
pace	4	50	0.04%	pace, pacing

Supplementary file 1; Summary table and bubble chart from thematic analysis of survey responses

sats	4	50	0.04%	sat, sats
wrong	5	50	0.04%	wrong, wrongly
horrible	8	50	0.04%	horrible
maybe	5	50	0.04%	maybe
recognition	11	50	0.04%	recognition
unsure	6	50	0.04%	unsure
persistent	10	50	0.04%	persist, persistence, persisted, persistent, persisting, persists
probably	8	50	0.04%	probability, probable, probably
side	4	50	0.04%	side, sided, sides
traumatic	9	50	0.04%	traumatic, traumatized, traumatizing
chronic	7	49	0.04%	chronic, chronically
caught	6	49	0.04%	caught
couldnâ	7	49	0.04%	couldnâ
fog	3	49	0.04%	fog
half	4	49	0.04%	half
minutes	7	49	0.04%	minute, minutes
appreciate	10	49	0.04%	appreciate, appreciated, appreciating, appreciation, appreciative
dizziness	9	49	0.04%	dizziness, dizzy
facebook	8	48	0.04%	facebook
passing	7	48	0.04%	'pass, pass, passed, passes, passing
busy	4	48	0.04%	business, businesses, busy
incredibly	10	48	0.04%	incredible, incredibly
learning	8	47	0.04%	learn, learned, learning
cycling	7	47	0.04%	cycle, cycles, cycling
horrendous	10	47	0.04%	horrendous
lockdown	8	47	0.04%	lockdown
hold	4	47	0.04%	hold, holding, holds
list	4	46	0.03%	list, listed, listing
shopping	8	46	0.03%	shop, shopping, shops
community	9	46	0.03%	communities, community
unless	6	46	0.03%	'unless, unless
cant	4	46	0.03%	cant
nobody	6	46	0.03%	nobody
none	4	46	0.03%	none
required	8	46	0.03%	require, required, requirements, requires, requiring
risk	4	46	0.03%	risk, risked, risking, risks

Supplementary file 1; Summary table and bubble chart from thematic analysis of survey responses

goes	4	45	0.03%	goes
instead	7	45	0.03%	instead
rehab	5	45	0.03%	rehab
sob	3	45	0.03%	sob
soon	4	45	0.03%	soon
hit	3	45	0.03%	hit, hits, hitting
socially	8	45	0.03%	social, socially
upsetting	9	45	0.03%	upset, upsets, upsetting
contracting	11	45	0.03%	contract, contracted, contracting
suspected	9	45	0.03%	suspect, suspected, suspectedly, suspecting, suspects
anti	4	44	0.03%	anti
apart	5	44	0.03%	apart
doesnâ	6	44	0.03%	doesnâ
either	6	44	0.03%	either
knew	4	44	0.03%	knew
paramedics	10	44	0.03%	paramedic, paramedics
ignoring	8	44	0.03%	ignorance, ignorant, ignore, ignored, ignores, ignoring
carrying	8	43	0.03%	carried, carries, carry, carrying
phased	6	43	0.03%	phase, phased, phases, phasing
number	6	43	0.03%	number, numbers
sit	3	43	0.03%	sit, sitting
gave	4	43	0.03%	gave
ability	7	42	0.03%	abilities, ability
fighting	8	42	0.03%	'fight, fight, fighting
mind	4	42	0.03%	mind, mindful, mindfully, minds
reason	6	42	0.03%	reason, reasonable, reasonably, reasoned, reasons
100	3	42	0.03%	100
legs	4	42	0.03%	leg, legs
plus	4	42	0.03%	plus
pretty	6	42	0.03%	pretty
saying	6	42	0.03%	saying
shielding	9	42	0.03%	shield, shielded, shielding
hubs	4	42	0.03%	hub, hubs
tasks	5	42	0.03%	task, tasks
situation	9	41	0.03%	situation, situations
weight	6	41	0.03%	weight, weights

Supplementary file 1; Summary table and bubble chart from thematic analysis of survey responses

desperate	9	41	0.03%	desperate, desperately
financial	9	41	0.03%	financial, financially
morning	7	41	0.03%	morning, mornings
uncertain	9	41	0.03%	uncertain
hands	5	41	0.03%	hand, handed, handfuls, hands
examination	11	41	0.03%	examination, examinations, examine, examined
recently	8	41	0.03%	recent, recently
triggered	9	41	0.03%	trigger, triggered, triggering, triggers
communication	13	41	0.03%	communicate, communicated, communication, communications
flow	4	41	0.03%	flow, flowed, flowing, flows
referral	8	41	0.03%	referral, referrals
remains	7	41	0.03%	remain, remained, remaining, remains
kept	4	40	0.03%	kept
pre	3	40	0.03%	pre
prior	5	40	0.03%	prior
throughout	10	40	0.03%	throughout
young	5	40	0.03%	young
late	4	40	0.03%	late, lately
surviving	9	40	0.03%	'surviving', survive, survived, surviving
response	8	40	0.03%	response, responses, responsibility, responsible, responsive
absolutely	10	40	0.03%	absolute, absolutely
moderate	8	40	0.03%	moderate, moderately
challenging	11	39	0.03%	challenge, challenges, challenging
daughter	8	39	0.03%	daughter, daughters
ages	4	39	0.03%	age, aged, ageing, ages
significantly	13	39	0.03%	significance, significant, significantly
love	4	39	0.03%	love, loved, lovely
rang	4	39	0.03%	rang, range, ranged, ranging
signs	5	39	0.03%	sign, signed, signing, signs
mask	4	39	0.03%	mask, masked, masking, masks
strangely	9	39	0.03%	strange, strangely
certain	7	39	0.03%	certain, certainly
distressing	11	39	0.03%	distress, distressed, distressing

Supplementary file 1; Summary table and bubble chart from thematic analysis of survey responses

missed	6	39	0.03%	miss, missed, missing
profession	10	39	0.03%	profession, professions
concentrate	11	39	0.03%	concentrate, concentrated, concentrating, concentration
surprising	10	39	0.03%	surprise, surprised, surprising, surprisingly
emerging	8	39	0.03%	emerge, emerged, emergencies, emergency, emerges, emerging
line	4	39	0.03%	line, lined, lines
small	5	39	0.03%	small
wife	4	39	0.03%	wife
yes	3	39	0.03%	yes
admission	9	39	0.03%	admission, admissions
mood	4	39	0.03%	mood, moods
forward	7	38	0.03%	forward, forwarded, forwards
facts	5	38	0.03%	fact, facts
seek	4	38	0.03%	seek, seeking
worsening	9	38	0.03%	worsen, worsened, worsening, worsens
close	5	38	0.03%	close, closed, closely, closing
capacity	8	38	0.03%	capacity
hear	4	38	0.03%	hear, hearing
prolonged	9	38	0.03%	prolonged
vulnerable	10	38	0.03%	vulnerability, vulnerable
important	9	38	0.03%	import, importance, important, importantly
existent	8	37	0.03%	exist, existant, existed, existence, existent, existing, exists
2020	4	37	0.03%	2020
nice	4	37	0.03%	nice
pay	3	37	0.03%	pay, paying
pulmonary	9	37	0.03%	pulmonary
relieved	8	37	0.03%	relieve, relieved, reliever
secondary	9	37	0.03%	secondary
wheezing	8	37	0.03%	wheeze, wheezing
plays	5	37	0.03%	play, played, playful, playing, plays
accept	6	37	0.03%	accept, acceptable, acceptance, accepted, accepting
review	6	37	0.03%	review, reviewed, reviewing, reviews
considering	11	37	0.03%	consider, considered,

Supplementary file 1; Summary table and bubble chart from thematic analysis of survey responses

				considering
lightly	7	37	0.03%	light, lightly
sadness	7	37	0.03%	sad, sadly, sadness
must	4	36	0.03%	must
past	4	36	0.03%	past
massive	7	36	0.03%	massive, massively
occasions	9	36	0.03%	occasion, occasions
sensation	9	36	0.03%	sensation, sensations
type	4	36	0.03%	type, typed, types
link	4	36	0.03%	link, linked, linking, links
private	7	36	0.03%	private, privately
air	3	36	0.03%	air, aired
losing	6	35	0.03%	lose, losing
noticing	8	35	0.03%	noticeable, notice, noticeable, noticed, noticing
garden	6	35	0.03%	garden, gardened, gardener, gardening, gardens
stage	5	35	0.03%	stage, stages
barely	6	35	0.03%	bare, barely
survey	6	35	0.03%	survey, surveys
tail	4	35	0.03%	tail, tail', tailed
deep	4	35	0.03%	deep
spoke	5	35	0.03%	spoke
unsupported	11	35	0.03%	unsupported
within	6	35	0.03%	within
words	5	34	0.03%	word, wording, words
repeats	7	34	0.03%	repeat, repeated, repeatedly, repeating, repeats
thereâ	6	34	0.03%	thereâ
uncertainty	11	34	0.03%	uncertainties, uncertainty
gradually	9	33	0.02%	gradual, gradually
angry	5	33	0.02%	angry
drs	3	33	0.02%	drs
eventually	10	33	0.02%	eventually
everyday	8	33	0.02%	everyday
four	4	33	0.02%	four
inflammation	12	33	0.02%	inflammation
ring	4	33	0.02%	ring, ringing
wearing	7	33	0.02%	wear, wearing, wears
ease	4	33	0.02%	ease, eased, eases, easing
except	6	33	0.02%	except, exception
infectious	10	33	0.02%	infectious, infectiousness

Supplementary file 1; Summary table and bubble chart from thematic analysis of survey responses

sort	4	33	0.02%	sort, sorted, sorting, sorts
allowed	7	33	0.02%	allow, allowed, allowing, allows
happy	5	33	0.02%	happiness, happy
strength	8	33	0.02%	strength, strengths
distancing	10	33	0.02%	distance, distanced, distances, distancing
form	4	33	0.02%	form, formed, forms
heavy	5	32	0.02%	heaviness, heavy
assuming	8	32	0.02%	assume, assumed, assumes, assuming
shocking	8	32	0.02%	shock, shocked, shocking, shockingly
basically	9	32	0.02%	basic, basically
drop	4	32	0.02%	drop, dropped, dropping, drops
note	4	32	0.02%	note, notes
obviously	9	32	0.02%	obvious, obviously
strongly	8	32	0.02%	strong, strongly
afterwards	10	32	0.02%	afterward, afterwards
earlier	7	32	0.02%	'earlier', earlier
example	7	32	0.02%	example, examples
haul	4	32	0.02%	haul, haul'
build	5	32	0.02%	build, building, buildings, builds
complications	13	32	0.02%	complicated, complicating, complication, complications
disappointed	12	32	0.02%	disappointed, disappointing, disappointment
bother	6	32	0.02%	bother, bothered, bothering, bothers
drink	5	32	0.02%	drink, drinking, drinks
date	4	32	0.02%	date, dates
non	3	32	0.02%	non
via	3	32	0.02%	via
food	4	32	0.02%	food, foods
safe	4	32	0.02%	safe, safely
miles	5	31	0.02%	mile, miles
worker	6	31	0.02%	worker, workers
resources	9	31	0.02%	resource, resources
asthmatic	9	31	0.02%	asthmatic, asthmatics
big	3	31	0.02%	big
dry	3	31	0.02%	dry
forgotten	9	31	0.02%	forgotten

Supplementary file 1; Summary table and bubble chart from thematic analysis of survey responses

partner	7	31	0.02%	partner
rollercoaster	13	31	0.02%	rollercoaster
today	5	31	0.02%	today
attended	8	31	0.02%	attend, attended, attending
stating	7	31	0.02%	state, stated, states, stating
avoid	5	31	0.02%	avoid, avoidable, avoided, avoiding
lying	5	31	0.02%	lie, lied, lies, lying
wards	5	31	0.02%	ward, wards
glad	4	31	0.02%	glad, gladly
mention	7	31	0.02%	mention, mentioned, mentioning
large	5	30	0.02%	large, largely
flares	6	30	0.02%	'flare, flare, flared, flares
prevent	7	30	0.02%	prevent, preventative, prevented, preventer, preventing, prevention, prevents
confidence	10	30	0.02%	confidence, confident, confidently
length	6	30	0.02%	length, lengths
process	7	30	0.02%	process, processed
describe	8	30	0.02%	describe, described, describes, describing
specific	8	30	0.02%	specific, specifically
heard	5	30	0.02%	heard
hot	3	30	0.02%	hot
palpitations	12	30	0.02%	palpitations
panic	5	30	0.02%	panic
sons	4	30	0.02%	son, sons
steps	5	29	0.02%	step, steps
along	5	29	0.02%	along
area	4	29	0.02%	area, areas
coronavirus	11	29	0.02%	coronavirus
fed	3	29	0.02%	fed
impossible	10	29	0.02%	impossible
june	4	29	0.02%	june
spoken	6	29	0.02%	spoken
therefore	9	29	0.02%	therefore
understood	10	29	0.02%	understood
haulers	7	29	0.02%	hauler, haulers, haulers'
watching	8	29	0.02%	'watching, watch, watched, watchful, watching
openly	6	29	0.02%	open, opened, opening,

Supplementary file 1; Summary table and bubble chart from thematic analysis of survey responses

				openly, openness
refusing	8	29	0.02%	refuse, refused, refuses, refusing
enjoy	5	29	0.02%	enjoy, enjoyable, enjoyed, enjoying, enjoyment
eye	3	29	0.02%	eye, eyes
leads	5	29	0.02%	lead, leading, leads
clots	5	28	0.02%	clot, clots, clotting
dog	3	28	0.02%	dog, dogs, dogs'
colleagues	10	28	0.02%	colleague, colleagues
restricted	10	28	0.02%	restricted, restricting, restrictions, restrictive, restricts
ive	3	28	0.02%	ive, ives
amazingly	9	28	0.02%	amazes, amazing, amazingly
acute	5	28	0.02%	acute, acutely
school	6	28	0.02%	school, schools
joining	7	28	0.02%	'joined, join, joined, joining
major	5	28	0.02%	major, majority, majors
alive	5	28	0.02%	alive
mostly	6	28	0.02%	mostly
saw	3	28	0.02%	saw
simple	6	28	0.02%	simple
voice	5	28	0.02%	voice
ecg	3	28	0.02%	ecg, ecgs
compared	8	27	0.02%	comparable, comparatively, compare, compared, comparing
appetite	8	27	0.02%	appetite
horrific	8	27	0.02%	horrific
paracetamol	11	27	0.02%	paracetamol
syndrome	8	27	0.02%	syndrome
raised	6	27	0.02%	raise, raised, raises, raising
disabled	8	27	0.02%	disability, disabled, disabling
falling	7	27	0.02%	fall, falling, falls
pandemic	8	27	0.02%	pandemic, pandemics
education	9	26	0.02%	educate, educated, educating, education
appropriate	11	26	0.02%	appropriate, appropriately
studying	8	26	0.02%	studied, studies, study, studying
draining	8	26	0.02%	drained, draining
varied	6	26	0.02%	varied, varies, vary, varying
honestly	8	26	0.02%	honest, honestly

Supplementary file 1; Summary table and bubble chart from thematic analysis of survey responses

parents	7	26	0.02%	parent, parents
smoke	5	26	0.02%	smoke, smoked, smoking
standing	8	26	0.02%	stand, standing
hurts	5	26	0.02%	hurt, hurtful, hurting, hurts
spend	5	26	0.02%	spend, spending, spends
battle	6	26	0.02%	battle, battled, battles, battling
unexpectedly	12	26	0.02%	unexpectedly, unexpected, unexpectedly
february	8	26	0.02%	february
guilty	6	26	0.02%	guilty
isnâ	4	26	0.02%	isnâ
multiple	8	26	0.02%	multiple
mum	3	26	0.02%	mum
upper	5	26	0.02%	upper
wonâ	4	26	0.02%	wonâ
yoga	4	26	0.02%	yoga
amount	6	25	0.02%	amount, amounts
imagining	9	25	0.02%	imagination, imagine, imagining
memory	6	25	0.02%	memories, memory
neurology	9	25	0.02%	neurological, neurology
additional	10	25	0.02%	addition, additional, additionally
dose	4	25	0.02%	dose, doses
single	6	25	0.02%	single, singled
centre	6	25	0.02%	centre, centred, centres
request	7	25	0.02%	request, requested, requesting, requests
forgetful	9	25	0.02%	forget, forgetful, forgetfulness, forgetting
basis	5	25	0.02%	basis
blue	4	25	0.02%	blue
cv19	4	25	0.02%	cv19
discomfort	10	25	0.02%	discomfort
episodes	8	25	0.02%	episode, episodes
frequent	8	25	0.02%	frequent, frequently
guidelines	10	25	0.02%	guidelines
icu	3	25	0.02%	icu
journey	7	25	0.02%	journey
nose	4	25	0.02%	nose
potential	9	25	0.02%	potential, potentially
annoying	8	25	0.02%	annoyance, annoyed,

Supplementary file 1; Summary table and bubble chart from thematic analysis of survey responses

				annoying
directed	8	25	0.02%	direct, directed, directing, direction, directly
round	5	25	0.02%	round, rounds
shower	6	25	0.02%	shower, showered, showering, showers
conversation	12	25	0.02%	conversation, conversations
members	7	25	0.02%	member, members
dreadful	8	25	0.02%	dread, dreadful, dreadfully, dreading
copd	4	24	0.02%	copd
easy	4	24	0.02%	easy
january	7	24	0.02%	january
nowhere	7	24	0.02%	nowhere
stomach	7	24	0.02%	stomach
details	7	24	0.02%	detail, detailed, details
therapy	7	24	0.02%	therapies, therapy
individual	10	24	0.02%	individual, individually, individuals
temp	4	24	0.02%	temp, temps
ride	4	24	0.02%	ride, rides, riding
aid	3	24	0.02%	aid, aide, aided, aiding, aids
books	5	24	0.02%	book, booked, booking, books
vitamins	8	24	0.02%	vitamin, vitamins
ensure	6	23	0.02%	ensure, ensuring
news	4	23	0.02%	news, news'
pulse	5	23	0.02%	pulse, pulses
doubt	5	23	0.02%	doubt, doubted, doubtful, doubting, doubts
training	8	23	0.02%	train, trained, training, trains
updates	7	23	0.02%	update, updated, updates
assistance	10	23	0.02%	assist, assistance, assistant, assistants
sound	5	23	0.02%	sound, sounded, sounding, soundly, sounds
999	3	23	0.02%	999
afraid	6	23	0.02%	afraid
fast	4	23	0.02%	fast
gpâ	3	23	0.02%	gpâ
relief	6	23	0.02%	relief
simply	6	23	0.02%	simply
spent	5	23	0.02%	spent
tachycardia	11	23	0.02%	tachycardia

Supplementary file 1; Summary table and bubble chart from thematic analysis of survey responses

weird	5	23	0.02%	weird
world	5	23	0.02%	world
email	5	23	0.02%	email, emailed, emailing, emails
fill	4	23	0.02%	fill, filled, filling, fills
rule	4	23	0.02%	rule, ruled, rules, ruling
sweats	6	23	0.02%	sweat, sweated, sweating, sweats
effort	6	23	0.02%	effort, efforts
practitioner	12	23	0.02%	practitioner, practitioners
send	4	23	0.02%	send, sending, sends
aftercare	9	22	0.02%	aftercare
hell	4	22	0.02%	hell
onset	5	22	0.02%	onset
primary	7	22	0.02%	primary
six	3	22	0.02%	six
somewhat	8	22	0.02%	somewhat
sympathetic	11	22	0.02%	sympathetic
underlying	10	22	0.02%	underlying
various	7	22	0.02%	various
exactly	7	22	0.02%	exact, exacted, exactly
cry	3	22	0.02%	cried, cry, crying
intermittent	12	22	0.02%	intermittent, intermittently
fairly	6	22	0.02%	fair, fairly
programme	9	22	0.02%	programme, programmes
trip	4	22	0.02%	trip, trips
based	5	22	0.02%	base, based, bases
exacerbation	12	22	0.02%	exacerbate, exacerbated, exacerbates, exacerbation, exacerbations
shoulder	8	22	0.02%	shoulder, shoulders
death	5	21	0.02%	death, deaths
widely	6	21	0.02%	wide, widely
false	5	21	0.02%	false, falsely
fell	4	21	0.02%	fell, felling
recurring	9	21	0.02%	recur, recurred, recurring
organised	9	21	0.02%	organisation, organisations, organise, organised, organising
washing	7	21	0.02%	wash, washed, washes, washing
benefits	8	21	0.02%	benefit, benefited, benefits
brings	6	21	0.02%	bring, bringing, brings

Supplementary file 1; Summary table and bubble chart from thematic analysis of survey responses

attention	9	21	0.02%	attention
cancer	6	21	0.02%	cancer
empathy	7	21	0.02%	empathy
excellent	9	21	0.02%	excellent
meant	5	21	0.02%	meant
mouth	5	21	0.02%	mouth
psychological	13	21	0.02%	psychological, psychologically
room	4	21	0.02%	room
site	4	21	0.02%	site, sites
thatâ	5	21	0.02%	thatâ
together	8	21	0.02%	together
tough	5	21	0.02%	tough
useless	7	21	0.02%	useless
teacher	7	21	0.02%	teacher, teachers
rash	4	21	0.02%	rash, rashes
racing	6	21	0.02%	'racing', races, racing
hill	4	21	0.02%	hill, hills
apparent	8	20	0.01%	apparent, apparently
child	5	20	0.01%	child
feet	4	20	0.01%	feet
kidney	6	20	0.01%	kidney, kidneys
meds	4	20	0.01%	meds
mid	3	20	0.01%	mid
mucus	5	20	0.01%	mucus
necessary	9	20	0.01%	necessary
nervous	7	20	0.01%	nervous
outside	7	20	0.01%	outside
pleurisy	8	20	0.01%	pleurisy
ppe	3	20	0.01%	ppe
thousands	9	20	0.01%	thousands
youâ	4	20	0.01%	youâ
zero	4	20	0.01%	zero
fobbing	7	20	0.01%	'fobbed, fob, fobbed, fobbing
gasping	7	20	0.01%	gasp, gasping
scarring	8	20	0.01%	'scarring', scar, scarred, scarring
meet	4	20	0.01%	meet, meeting, meetings
deteriorating	13	20	0.01%	deteriorate, deteriorated, deteriorating, deterioration
indicate	8	20	0.01%	indicate, indicated, indicates, indicating, indication, indications, indicative,

Supplementary file 1; Summary table and bubble chart from thematic analysis of survey responses

				indicator
resolve	7	20	0.01%	resolve, resolved, resolves, resolving
reports	7	20	0.01%	report, reported, reporting, reports
cleaning	8	20	0.01%	clean, cleaning
gentle	6	20	0.01%	gentle, gently
touch	5	20	0.01%	touch, touched
gym	3	20	0.01%	gym, gyms
uncomfortable	13	20	0.01%	uncomfortable, uncomfortably
critical	8	20	0.01%	critical, critically, criticism, critics
order	5	20	0.01%	order, ordered, ordering
unpredictable	13	20	0.01%	unpredictability, unpredictable, unpredictably
depends	7	20	0.01%	depend, dependance, dependancy, dependant, depended, dependency, dependent, depending, depends
organs	6	20	0.01%	organ, organs
routine	7	20	0.01%	routine, routinely, routines
preparing	9	20	0.01%	preparation, prepare, prepared, preparing
knocks	6	20	0.01%	knock, knocked, knocking, knocks
accurate	8	19	0.01%	accurate, accurately
common	6	19	0.01%	common, commonly
opportunity	11	19	0.01%	opportunities, opportunity
text	4	19	0.01%	text, texting
ventolin	8	19	0.01%	ventolin, ventoline
counting	8	19	0.01%	count, counted, counting
ears	4	19	0.01%	ear, ears
occurring	9	19	0.01%	occur, occurring, occurred, occurring, occurs
anymore	7	19	0.01%	anymore
began	5	19	0.01%	began
dark	4	19	0.01%	dark
didnt	5	19	0.01%	didnt
housework	9	19	0.01%	housework
marathon	8	19	0.01%	marathon, marathons
stuck	5	19	0.01%	stuck
top	3	19	0.01%	top
matter	6	19	0.01%	matter, mattered, matters
household	9	19	0.01%	household, households

Supplementary file 1; Summary table and bubble chart from thematic analysis of survey responses

pattern	7	19	0.01%	pattern, patterns
fluid	5	19	0.01%	fluid, fluids
proactive	9	19	0.01%	proactive, proactively
heal	4	19	0.01%	heal, healed, healing
anyway	6	18	0.01%	anyway
arrange	7	18	0.01%	arrange, arranged, arranging
beyond	6	18	0.01%	beyond
coaster	7	18	0.01%	coaster
fortunate	9	18	0.01%	fortunate, fortunately
front	5	18	0.01%	front
guilt	5	18	0.01%	guilt
london	6	18	0.01%	london
ribs	4	18	0.01%	rib, ribs
shift	5	18	0.01%	shift, shifts
skin	4	18	0.01%	skin
tablets	7	18	0.01%	tablets
wasting	7	18	0.01%	waste, wasted, wasting
wider	5	18	0.01%	wider
climbing	8	18	0.01%	climb, climbed, climbing
originally	10	18	0.01%	origin, original, originally
convinced	9	18	0.01%	convince, convinced, convincing
recommended	11	18	0.01%	recommend, recommendation, recommendations, recommended, recommending
fluctuating	11	18	0.01%	fluctuate, fluctuated, fluctuates, fluctuating, fluctuations
consistently	12	18	0.01%	consistant, consisted, consistency, consistent, consistently
country	7	18	0.01%	countries, country
stories	7	18	0.01%	stories, story
qualify	7	18	0.01%	qualified, qualify, qualifying
swim	4	18	0.01%	swim, swimming, swims
pick	4	18	0.01%	pick, picked, picking
chat	4	18	0.01%	chat, chatted
hair	4	18	0.01%	hair, hairs
official	8	18	0.01%	'officially', official, officially
ten	3	18	0.01%	ten, tens
cook	4	18	0.01%	cook, cooked, cooking
mine	4	18	0.01%	mine, mines

Supplementary file 1; Summary table and bubble chart from thematic analysis of survey responses

trouble	7	18	0.01%	trouble, troubled, troubles, troubling
unfortunately	13	18	0.01%	unfortunate, unfortunately
cognitively	11	18	0.01%	cognition, cognitive, cognitively
diet	4	18	0.01%	diet, dieting, diets
experts	7	18	0.01%	expert, experts, experts'
hopeless	8	18	0.01%	hopeless, hopelessly, hopelessness
traumatised	11	18	0.01%	traumatised, traumatises, traumatising
fingers	7	18	0.01%	finger, fingers
reluctant	9	18	0.01%	reluctance, reluctant
urgent	6	18	0.01%	urgent, urgently
spread	6	17	0.01%	spread, spreading
video	5	17	0.01%	video, videos
message	7	17	0.01%	message, messages, messaging
decided	7	17	0.01%	decide, decided, deciding
arms	4	17	0.01%	arm, arms
driving	7	17	0.01%	drive, driving
options	7	17	0.01%	option, options
ventilator	10	17	0.01%	ventilated, ventilating, ventilation, ventilator, ventilators
crash	5	17	0.01%	crash, crashed, crashing
prove	5	17	0.01%	prove, proved, proving
arenã	5	17	0.01%	arenã
awaiting	8	17	0.01%	awaiting
cardiac	7	17	0.01%	cardiac
easier	6	17	0.01%	easier
kids	4	17	0.01%	kids
per	3	17	0.01%	per
ptsd	4	17	0.01%	ptsd
receptionist	12	17	0.01%	receptionist, receptionists
reliable	8	17	0.01%	reliable
roller	6	17	0.01%	roller
contagious	10	17	0.01%	contagious, contagiousness
neck	4	17	0.01%	neck, neck'
odd	3	17	0.01%	odd, oddly, odds
address	7	17	0.01%	address, addressed, addresses, addressing
approach	8	17	0.01%	approach, approaching

Table E1: symptoms in a) whole cohort; b) Hospitalised patients and average time between onset of symptoms and completion of survey.

Symptoms n (%)	Whole cohort n=3023	Self- treatment at home cohort n=2644	Hospitalised patients n=376	p-value
Breathing problems - for example chest tightness, or struggling to breathe while resting or being active	3027 (92.0)	2646 (92.1)	381 (91.4)	0.61 (X)
Changes in mood, or anxiety or depression	1417 (43.1)	1214 (42.3)	176 (42.2)	0.70 (X)
Cough	1392 (42.3)	1207(42.0)	185 (44.4)	0.36 (X)
Extreme tiredness (fatigue) or lack of energy	2739 (83.3)	2394 (83.3)	345 (82.7)	0.76(X)
Hair loss	346 (10.5)	304 (10.6)	42 (10.1)	0.75 (X)
Loss of appetite or weight loss	755 (22.9)	657 (22.9)	98 (23.5)	0.77 (X)
Loss of taste or smell (anosmia)	936 (28.4)	808 (28.1)	128 (31.9)	0.28 (X)
Muscle weakness or joint stiffness	1662 (50.5)	1449 (50.4)	213 (51.1)	0.81 (X)
Nightmares or flashbacks	432 (13.1)	379 (13.2)	53 (12.7)	0.79 (X)
Problems with mental abilities; e.g. not being able to remember some events, think clearly and being forgetful	1508 (45.8)	1325 (46.1)	183 (43.9)	0.39 (X)
Sleep problems	1520 (46.2)	1341 (46.7)	179 (42.9)	0.15(X)
Symptoms of post-traumatic stress disorder (PTSD) - for example, feelings of isolation, irritability and guilt	578 (17.6)	503 (17.5)	75 (18.0)	0.81 (X)
Average length of time between onset of symptoms and completing survey (days)	105.9±53.0	105.7±55.7	106.8±61.5	0.69 (¥)

Data are presented as n (%) or mean ±. P values of <0.05 are taken to indicate statistical significance and are marked in bold. X= Chi square test used, ¥= t-test used. Where numbers do not total 100% missing values are due to questions unanswered by participant. Changes of mood are taken to indicate a negative change in mood (i.e. more anxious, more depressed, etc)

Table E2: Length of stay of hospitalised patient, ventilatory support and quality of communication/information received

	Hospitalised patients n=417
How long were you in hospital for? Less than 1 week 1 to 2 weeks 2 to 4 weeks More than 4 weeks	238 (57.1%) 106 (25.4%) 51 (12.2%) 22 (5.3%)
Were you able to breathe by yourself throughout your treatment for symptoms of COVID-19? Yes - I was able to breathe by myself without any additional support (apart from any medication that I normally take) Yes - I was able to breathe by myself with some support (e.g. face mask or tube under your nose that delivers oxygen, CPAP machine) No - I stopped being able to breathe by myself and needed mechanical support (e.g. ventilator tube that is put into your airways to help you breathe, ECMO life support where blood is pumped through a machine that acts as your lungs)	140 (33.6%) 210 (50.4%) 44 (10.6%)
How long were you in ITU for? Less than 3 days 4 to 7 days 7 to 14 days More than 14 days	n=102 16 (15.7%) 33 (32.4%) 32 (31.4%) 20 (19.6%)
Patient reported quality of communication/information received during hospital stay How clear was the information being communicated? How useful was the information to you? How timely was the communication? How empathetic was the communication?	5.6±2.9 5.3±3.0 5.4±3.0 6.4±3.1
Did you get a rehabilitation plan when you left hospital?	Yes= 29 (7.0%) No= 386 (92.6%)

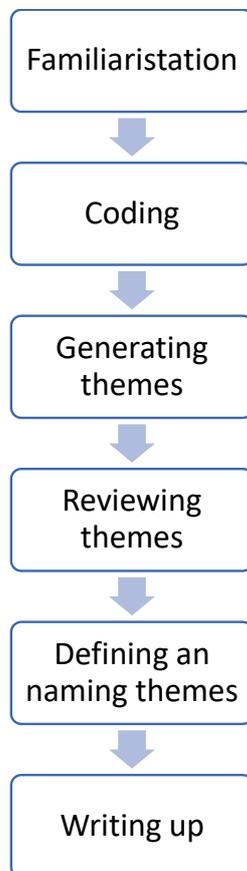
Data are presented as n (%) or mean ±. P values of <0.05 are taken to indicate statistical significance and are marked in bold. Where numbers do not total 100% missing values are due to questions unanswered by participant.

Table E3: Experience of care received during and after COVID-19 and ability to cope in a) whole cohort; b) hospitalised patients

	Whole cohort n=3290	Hospitalised patients n=417	P-value
Have you spoken to Nurse/GP?			
Yes	2357 (71.6)	282(67.6)	
No	901 (27.4)	108 (25.9)	0.21(X)
Did your GP or nurse tell you about *things you can do* to help your recovery?			
Yes	919 (27.9)	120 (28.8)	0.16(X)
No	1428 (43.4)	161 (38.6)	
Patient reported quality of communication/information received after COVID-19			
How clear was the information being communicated?	5.6±2.7	6.0±2.7	0.002(¥)
How useful was the information to you?	4.7±2.8	5.4±2.8	P<0.001(¥)
How timely was the communication?	4.9±3.0	5.3±3.0	0.025(¥)
How empathetic was the communication?	6.1±3.1	6.6±3.0	0.004(¥)
How important are each of the following for you?			
General information on difficulties after COVID-19	8.9±1.7	9.1±1.8	0.88(¥)
Advice from healthcare professionals on managing difficulties after COVID-19	9.0±1.7	9.1±1.8	0.22(¥)
The latest medical research on difficulties after COVID-19	8.9±1.7	8.9±1.9	0.44(¥)
Reading about other people that have difficulties after COVID-19 and their experiences	8.4±2.0	8.4±2.1	0.35(¥)
Talking to other people with difficulties after COVID-19 and sharing experiences	7.4±2.6	7.8±2.4	0.18(¥)
Do you receive any practical help with your difficulties after COVID-19 on a regular basis?			
Yes, from someone living in my household	1719 (52.2)	247 (59.2)	
Yes, from someone living in another household	441 (13.4)	79 (18.9)	P<0.001
No, I don't need help	850 (25.8)	56 (13.4)	
No, I can't get help	268 (8.1)	33 (7.9)	
How much do you feel you can cope with your life after COVID-19?			
Completely	269 (8.2)	25 (6.0)	
Mostly	1206 (36.7)	160 (38.4)	
Partly	1279 (38.9)	162 (38.8)	0.40
Very little	454 (13.8)	63 (15.1)	
Not at all	82 (2.5)	12 (2.9)	

Data are presented as n (%) or mean ±. P values of <0.05 are taken to indicate statistical significance and are marked in bold. X= Chi square test used, ¥= t-test used. Where numbers do not total 100% missing values are due to questions unanswered by participant.

Six step process of thematic analysis as described by Braun and Clarke



Braun V, Clarke V.,. Using thematic analysis in psychology. *Qualitative Research in Psychology* 2006; 3:77-101