Nottingham & Nottinghamshire

Health and Social Care Needs of People with Long COVID

August 2021

Funded by the East Midlands Academic Health Science Network
In collaboration with **Self Help UK**

> *‘I have had no real help from my GP or anybody else and have had to do my own research on the Internet and trial things for controlling the symptoms’*

Comment from participant

Contents

Who are Healthwatch Nottingham & Nottinghamshire?

Healthwatch Nottingham & Nottinghamshire is the independent patient and public champion that holds health and social care services more accountable to their communities for the services they commission and provide.

We have 3 key roles:

Scrutiny of local health and care commissioners to ensure that they: listen to the public, provide excellent care, provide quality signposting and are totally transparent

Make a difference: We collect & provide insight from patients & communities and use these to make recommendations to improve services for the public. We will then scrutinise how this insight helps to influence improvements.

To work in partnership across local, regional, and national networks of Healthwatch and the CQC to ensure big issues/opportunities are acted upon & best practice is shared, whilst ensuring that our independence is maintained

Why is it important?

You are the expert on the services you use, so you know what is done well and what could be improved.

Your comments allow us to create an overall picture of the quality of local services. We then work with the people who design and deliver health and social care services to help improve them.

How do I get involved?

We want to hear your comments about services such as GPs, home care, hospitals, children and young people's services, pharmacies, and care homes.

You can have your say by:

☎ 0115 956 5313

www.hwnn.co.uk

@_HWNN

Facebook.com/HealthwatchNN

Healthwatch Nottingham & Nottinghamshire
Unit 1, Byron Business Centre,
Duke Street,
Hucknall,
Nottinghamshire,
NG15 7HP

Report signed off by

Name	Position	Date
Ajanta Biswas	Vice Chair	July 2020

Executive summary

According to research 2 million people may have had Long COVID, showing that more than one third of people who had **COVID-19** reported symptoms lasting for at least 12 weeks (June 2021[1]). Long COVID is a new and complex syndrome affecting the health and quality of life of many people. Much remains unknown about the condition and more research is required to identify and understand Long COVID and the differences in experience throughout the population.

This report presents the lived experiences of people with Long COVID, identifying their ongoing symptoms and the response from health and social care services to meet their needs. It builds on the findings with recommendations to local health and social care service providers and commissioners.

Healthwatch Nottingham and Nottinghamshire and Self-Help UK were partially funded by the East Midlands Academic Health Science Network, to work with people who have Long COVID symptoms; and to develop their skills in survey design, analysis and report writing. The aim was to gather their experiences and report the findings to local health and social care service providers and commissioners.

A focus group was held in February 2021 with a small group of people experiencing Long COVID symptoms. The themes identified in the focus group shaped the question design of an online survey. HWNN gathered the views of 37 people from across Nottingham and Nottinghamshire in March 2021. The findings are discussed in line with the common themes that members of the Facebook COVID-19 Survivor's group identified and wanted to research. These themes included:

- Whether they were tested for COVID-19?
- Who they first contacted for treatment for COVID-19 and their experience of care?
- Whether they were hospitalised and their experience of care?
- The ongoing symptoms they are still experiencing.
- What support from health and social care would be helpful to meet their needs?

A total of seven people took part in the focus group, three of whom went onto to become volunteer researchers and attended the questionnaire design, analysis and report writing training and inputted into the design of the online survey. The survey was shared with members of the COVID-19 Survivors Facebook Group and more widely among statutory and voluntary organisations and the networks of Healthwatch Nottingham and Nottinghamshire and Self-Help UK. A total of 37 people responded to the online survey.

Limitations of the Survey

Given the nature of Long COVID, notably symptoms of fatigue, people with Long COVID may not have felt well enough to complete an online survey. This may explain the lower response rate. The survey could only be shared electronically and completed online due to COVID restrictions and social distancing. This would have been a barrier for people who have limited or no digital access.

---

[1] http://spiral.imperial.ac.uk/handle/10044/1/89844

Findings

Please note: There is no formally agreed definition for ongoing COVID-19 symptoms, and definitions overlap and are used interchangeably by health professionals and researchers. The definition used by the National Institute for Health and Care Excellence (NICE) is mentioned in the literature review, but for ease, the term ‘Long COVID’ will be used in this report and refers to people who have experienced ongoing symptoms related to COVID for 12 weeks or longer.

From our survey 9 out of 10 people thought they first contracted COVID-19 in 2020, while less than 1 out of 10 people thought they contracted COVID-19 in 2021. Just under two thirds of people were tested for COVID-19, just over a third of people were not tested, and this may be because testing was not readily available in the early part of 2020. Over half of the people surveyed contacted 111 and over a third of people contacted their GP when they first experienced symptoms of COVID-19. Over a third of people were referred or admitted to A & E/hospital by the GP, 111 or 999, while under a third were either sent home or advised to stay at home. Half of the people surveyed were happy with the care they received from primary care health professionals, although half of the people were unhappy with their care, citing misdiagnosis; or primary care providers giving conflicting or limited information; or not taking them seriously and not being able to refer them for specialist treatment and care. Hence, primary care providers need to show more sensitivity to the patients’ situation and an awareness of Long COVID symptoms.

9 out of 10 people in our survey experienced fatigue as the most common symptom of Long COVID, while 7 out of 10 people experienced brain fog and shortness of breath. Half of the people in our survey experienced achy limbs, headaches, and dizziness. Over a third of people said they experienced difficulty regulating temperature, while one fifth of people said they had a cough. Less than 1 in 10 people said they had reduced appetite, hair loss, poor mobility/inability to exercise, insomnia, increased heart rate, joint pain, and a rash. Other less reported symptoms were weight loss, difficulty swallowing and poor circulation.

Over three quarters of people surveyed said Long COVID has impacted their mental health and well-being. One third said they had anxiety and fear to go out or mix with people in case they catch COVID-19 again. Around one sixth of people felt they were not believed by primary care providers, while around 1 in 10 people were feeling emotional, frustrated, and depressed. This is due to the ongoing symptoms they are still experiencing; not receiving the treatment and care they need, and have not being able to do simple, normal everyday activities.

Three quarters of people in our survey said that a one stop Long COVID clinic for assessment and treatment would help meet their health needs as opposed to having many separate referrals. Currently only patients who were hospitalised with COVID receive treatment for respiratory conditions in the COVID clinic at the Queens Medical Centre. There is a Long COVID assessment clinic being piloted via GP referral. This clinic was established in March 2021 before our survey had been carried out. It is also important to note that is an assessment clinic and not a treatment clinic.

Just under half of the people surveyed said that more information is needed about Long COVID, with one third saying they would like online forums provided by health professionals with question-and-answer sessions and information sharing. Over half the people surveyed said they would like courses for managing pain/fatigue/symptoms.

Two fifths of the people surveyed said they would like peer to peer support or a self-help group, with one third of people saying they would like support by way of a helpline. A quarter of the people surveyed said they would like professional emotional and well-being support such as counselling or therapy, and support for the family.

While the literature review for this report highlights the need for more clinical and academic research around Long COVID, our research highlights the need to consider and include the lived experience of people with Long COVID in the research on an ongoing basis.

Recommendations

HWNN recommends immediate attention to the following:

- Primary health care providers to have greater awareness and recognition of Long COVID, and to understand the range of symptoms; and be able to refer and signpost patients to relevant support to manage those varied symptoms.
- The Integrated Care System (ICS) and Clinical Commissioning Groups (CCG) to commission appropriate rehabilitation and treatment services including commissioning of a one stop Long COVID clinic offering treatment for numerous and varied symptoms so that access to services is not impacted by a fragmented care pathway.
- The ICS and CCG to review and commission appropriate mental health support e.g., peer-to-peer self-help support and helpline, and fast track to professional counselling, therapy and emotional health and wellbeing support.
- Community Healthcare Providers to enhance and promote their current offer for courses on pain/fatigue/symptoms management, Your Covid recovery programme (referral by Health Professional), online and pre-recorded courses.
- National level: NHS England and ICS to provide more information about Long COVID for patients via an online forum run by health professionals, with question-and-answer sessions and information sharing (See Appendix 1 for the Nottingham Recovery from COVID-19 Research Platform (NoRCoRP).

Introduction

Healthwatch Nottingham & Nottinghamshire (HWNN) is the local independent patient and public champion. We hold local health and care leaders to account for providing excellent care by making sure they communicate and engage with local people, and are clear, meaningful, and transparent in their decision making.

We gather and represent the views of those who use health and social care services, particularly those whose voice is not often listened to. We use this information to make recommendations to those who have the power to make change happen.

Healthwatch Nottingham and Nottinghamshire (HWNN) and Self-Help UK (SHUK) were partially funded by East Midlands Academic Health Science Network (EMAHSN) to work with people with Long COVID to develop their skills in survey design, analysis and report writing. The aim was to be able to gather people's experiences of living with Long COVID, identify their symptoms and their feedback of the response of health and social care services in meeting their needs, and document these findings with recommendations in a report to be shared with local health and social care service providers and commissioners.

Background

How the project came about

The COVID-19 Survivors Group UK was set up as a Facebook page on 24th June 2020 with assistance from Self Help UK Nottingham (SHUK). Its aim is to enable its 1600 members who have recovered from COVID-19 to talk to each other to aid their growth, recovery, physical and mental wellbeing. The group was initially set up as a Facebook group for survivors to share their stories; for SHUK to post up to date and relevant information; and for group members to support one another. The group noticed they shared similar issues, so Healthwatch Nottingham and Nottinghamshire (HWNN) worked with Self Help UK to carry out research to explore these shared issues in more detail.

Why this project is important

According to research 2 million people may have had Long COVID, showing that more than one third of people who had **COVID-19** reported symptoms lasting for at least 12 weeks (June 2021[2]). Long COVID is a new and relatively unknown condition affecting the health and quality of life of many people and requires more research and understanding. Members of the Facebook COVID-19 Survivors group identified common themes they wanted us to examine, as already mentioned. These common themes included:

- Their experiences of COVID-19
- Feeling alone in having COVID-19
- Symptoms
- Long COVID becoming much more of an issue with some people having symptoms weeks and months later
- Response of health and social care providers

Many members of the COVID-19 Survivors group noted they were experiencing symptoms and health issues lasting many weeks and months after having the virus, which has impacted their lives and limited them in carrying out everyday activities and tasks. They also noted similar experiences

---

[2] http://spiral.imperial.ac.uk/handle/10044/1/89844

regarding the response of health and social care services in meeting their needs. HWNN wanted to see if similar issues were noted by other people experiencing Long COVID symptoms.

Whilst determining the implications of Long COVID on people's health, the project also aimed to empower people to understand the condition and to provide peer to peer support whilst enabling some of them to become researchers to directly communicate the needs of their community with Health Commissioners and decision makers.

Giving a voice to patients with lived experience is a powerful tool for understanding the nature of the condition, as well as the needs of people with Long COVID symptoms. By sharing their experience and insight of living with Long COVID, it will benefit health and social care agencies and the EMAHSN and inform future approaches for people with the condition.

People with Long COVID will also share the good practice and support they are receiving from health and social care in their locality with other group members. In this way, good practice will be spread.

What other literature and research says about this topic

Over 4.5 million people as of June 2021[3], in the UK have tested positive for COVID-19 since the pandemic began. The total number in Nottingham and Nottinghamshire was 88,300 (June 2021[4]). While many people recover from COVID-19, some people will go on to experience symptoms for longer periods. While there is no formally agreed definition, Long COVID is the term usually used to describe symptoms that last for longer than four weeks. Another term used is post-COVID-19 syndrome with signs and symptoms that develop during or after an infection consistent with COVID-19, continuing for more than 12 weeks and are not explained by an alternative diagnosis (NICE, 2020).

1.1 million people in UK private households were identified with self-reported long COVID (ONS April 2021[5]). Counting the actual number of people affected is problematic however, as most COVID-19 cases have no formal NHS record of their infection and were not given a Polymerase Chain Reaction (PCR) test, so there is not a reliable count regarding cases of infection or the subset with enduring symptoms.

Long COVID has found to be associated with 205 different symptoms related to 10 different systems in the body (NIHR Mar 2021[6]). Common symptoms include problems with concentration and memory (brain fog), fatigue, shortness of breath, chest pains, tightness, or heart palpitations (NHS England, 2021) and tend to overlap, meaning multiple systems within the body are affected to include the brain, kidneys, gut, liver, and skin.

Hence, Long COVID is proving to inhibit patients' daily activities and quality of life in ways not anticipated from the acute phase of illness. Some people are still needing help with personal care months later; some cannot carry out normal day to day activities and this can affect how they can care for their children, partner, or relatives. Moreover, it has hindered them in going back to work which impacts their finances (NIHR Mar 2021[5]).

In response, the Long COVID NHS plan for 2021/22[7] aims to invest £100 million to support those suffering from long COVID. This support includes an enhanced service for general practice to support long COVID care needs and enable consistent referrals. It will also establish 'paediatric hubs' to coordinate care for children and young people. Currently there are Long COVID pilot assessment clinics in England offering holistic assessment, and helping patients access the right specialist services. The Your COVID Recovery website and online rehabilitation service has also been launched (See Appendix 1 for Local and national health service support for people with Long COVID).

---

[3] https://coronavirus.data.gov.uk/details/cases

[4] https://www.nottinghamshire.gov.uk/care/coronavirus/local-outbreak-plan/covid-19-report-for-nottinghamshire

[5] https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/1april2021

[6] https://www.nihr.ac.uk/news/nihr-publishes-second-themed-review-on-long-covid/27232

[7] https://www.england.nhs.uk/coronavirus/publication/long-covid-the-nhs-plan-for-2021-22/

However, more research is needed to understand Long COVID and the differences in experience throughout the population, as much uncertainty remains around the condition. Agreement on measurement criteria and definitions of symptoms make it difficult to make comparisons between studies and hinders clinical consensus on what Long COVID is. It is also important to understand the prevalence of each symptom and their causes and gather more data on how long symptoms last (NIHR Mar 2021[8]).

There is an urgent need to research the diagnosis, treatments, prevention, and management for people with long-term effects from COVID-19 with a new approach focusing on delivering holistic and integrated care rather than by organ affected, or by disease, or a symptom-by-symptom management (ONS April 2021[9], NIHR March 2021[10]). Urgent research is needed to understand the risk factors for Long COVID so that treatment can be targeted better to demographically and clinically at-risk populations. Seldom heard voices are also not represented in the current evidence, so research needs to be targeted at vulnerable people (including older people and people with Learning Disabilities) as well as hard to reach groups including travellers and prison populations. NIHR also recommend that people living with Long COVID (who are experts by experience) should be equal partners in setting the research agenda. In response, £50 million has now been committed to supporting research directly designed to improve understanding of and deliver specific support to individuals affected by Long COVID (NHS England April 2021[11]).

To find out more about Nottingham University Hospitals (NUH) research examining the impacts and lasting effects of COVID-19 on patients and translating findings into new approaches to treatment to support their recovery, see Appendix 1.

---

[8] https://www.nihr.ac.uk/news/nihr-publishes-second-themed-review-on-long-covid/27232

[9] https://www.ons.gov.uk/news/news/newresearchimprovesourunderstandingofthelongtermimplicationsofcovid19

[10] https://www.nihr.ac.uk/news/nihr-publishes-second-themed-review-on-long-covid/27232

[11] https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/11/C1248- national-guidance-post-covid-syndrome-assessment-clinics-v2.pdf

Our approach

A literature review was carried out to understand the experiences of people recovering from COVID-19 and in seeking help from health and social care services. The literature review findings shaped the questions for conducting a focus group with people who have Long COVID symptoms. Members from the COVID-19 Survivors Facebook group and members of the public were invited to take part in the focus group and had to meet two criteria to be eligible. They had to have experienced ongoing COVID symptoms for more than three months and had tried to use services within Nottingham and Nottinghamshire to seek help for their condition.

The focus group was carried out on 27th January 2021 and seven people participated. The focus group discussion was recorded, transcribed, and then analysed to identify themes.

The findings from these themes were used to shape the questions for an online survey. Three focus group participants with lived experience of having Long COVID agreed to become volunteer researchers. They undertook questionnaire design training and further training to analyse the data and write up the report.

The online survey was created by the volunteer researchers and supported by HWNN who also worked with SHUK to edit it. The online survey was piloted and then shared with members from the COVID-19 Survivors Facebook group and wider public in Nottingham and Nottinghamshire through HWNN and SHUK contact databases.

The survey was circulated electronically to individuals and groups and via the HWNN website, and one participant was interviewed by telephone. The survey comprised comment boxes combined with tick box options. Responses were entered onto a secure SNAP survey link. This data was downloaded and analysed for themes and trends.

In March 2021, HWNN gathered the views of 37 people who experienced ongoing COVID symptoms for three months or more and had tried to use services within Nottingham and Nottinghamshire.

Of the 37 people who responded to the survey, 70.2% (n=26) were from Nottinghamshire, 24.3% (n=9) were from Nottingham City, and 5.4% (n=2) were from outside Nottinghamshire.

Of these, 36 people completed online surveys and 1 person had a telephone interview.

Tables showing the demographic data of the respondents are included at the end of the report in Appendix 2.

Summary of findings

The findings and themes that emerged from the focus group were used to shape the questions for the online survey. This report will not document the findings of the focus group to avoid repetition. Instead, the report will document the findings taken from the online survey. Please note these findings reflect similar findings of those of the focus group and are in line with the common themes the Facebook COVID-19 Survivors group identified and wanted to research. Where appropriate it will mention the focus group findings specifically.

While the findings in the tables show the breakdown in numbers, the value of this report is in the more detailed responses to the survey which will shape the recommendations.

Findings from the survey responses and focus group

The findings will highlight:

- When people first experienced COVID symptoms, whether they were tested and the outcome.
- The main ongoing symptoms people experienced since having COVID-19.
- How health and social care services responded to them when they first contracted COVID-19.
- The support they received since having COVID-19.
- The type of support they would like to receive to meet their healthcare needs.

Question: When did you first experience COVID-19 symptoms? Were you tested for COVID-19 and was the test positive?

Month	Tested	Positive	Negative	Not tested	Total
Jan 2020	0	N/A	N/A	1	1
Feb 2020	0	N/A	N/A	2	2
Mar 2020	5	4	1	7	12
Apr 2020	1	0	1	4	5
Jul 2020	1	1			1
Sep 2020	1	1	0	0	1
Oct 2020	8	8	0	0	8
Nov 2020	3	3	0	0	3
Dec 2020	1	1	0	0	1
Jan 2021	3	3	0	0	3
TOTAL	**23**	**21**	**2**	**14**	**37**

Table number 1 – source all respondents (n=37)

Of the 37 people who responded to our survey, most people 91.9%, (n=34) thought they contracted COVID-19 in 2020, while a few people 8.1%, (n=3) thought they contracted COVID-19 in 2021.

While many people 62.1% (n=23) were tested for COVID-19 there were some 37.8% (n=14) who were not tested, and this may be because testing was not available in the early part of 2020. For example, *'There was no test available at the time so we couldn't confirm that I had COVID'.*

Of the 23 people who were tested, 21 people said they tested positive, and 2 people said they had tested negative for COVID-19.

Question: When you first developed symptoms of COVID-19 did you contact any of the following for support?

Service	Number	Percent
111	20	54.0%
GP	14	37.8%
None	9	24.3%
999	3	8.1%
Track & Trace	1	2.7%
Other	1	2.7%

Table number 2 – source all respondents (n=37) Total percentages add up to more than 100% because some respondents accessed more than one source of advice and support.

Of the 37 people who responded to our online survey, 54% (n=20) people contacted the 111 service, and 37.8% (n=14) people contacted their GP for support when they first thought they had contracted COVID-19, while 8.1% (n=3) people contacted 999, 2.7% (n=1) person contacted Track and Trace and 2.7% (n=1) person contacted 'other' service but did not specify. 24.3% (n=9) people did not contact any services for support.

Question: Did you receive the support you needed from the above services?

Support received	Number	Percent
Yes	17	45.9%
No	17	45.9%
Not answered	3	8.1%
Total	**37**	**100%**

Table number 3 – source all respondents (n=37)

Out of the 37 respondents, 45.9% (n=17) stated they did receive the support they needed from the services they contacted, when they first experienced COVID-19 symptoms. For example, *'When paramedics came, they were brilliant'.* and *'My GP was a support line'* and *'I received advice, psychological support and a recovery plan [from GP]'.*

45.9% (n=17) people stated they did not receive the support they needed from the services they contacted when they first experienced COVID-19 symptoms.

8.1% (n=3) did not answer this question.

Question: In what way did you or didn’t you receive the support you needed? Please explain your answer

In what way did you or didn’t you receive the support you needed?	Number	Percent
Referred or admitted to A & E/hospital by the GP, 111 or 999	14	37.8%
Sent home or told to stay at home	10	27.0%
GP/health professional were helpful	8	20.5%
Given specialist procedures	8	20.5%
Health professional was not helpful	6	15.3%
Misdiagnosed	5	12.8%
Given conflicting or limited information	5	12.8%
Not taken seriously	4	10.2%
Given advice/psychological support and a recovery plan	3	7.6%

Table number 4 – source all respondents (n=37) Total percentages add up to more than 100% because some respondents gave multiple responses.

37.8% (n=14) people were referred to hospital or admitted to A & E by their GP, 111 or 999, with some of these 21.6% (n=8) receiving specialist procedures such as: a Pulmonary Ventilation/Perfusion (VQ) lung scan, treatment in the Intensive Care Unit, X-rays, CT scan, gas test for oxygen. For example, *‘When I got there, I was taken straight to Intensive Care Unit’* and *‘My GP sent me for a chest x-ray and then a CT scan which showed I have punctured (or collapsed) lungs’.*

Over a quarter of respondents 27% (n=10) were sent home or told to stay at home, which was the advice given during the early part of the pandemic to limit the spread of contagion. *‘I did not receive any support but told to manage the condition at home and not attend a surgery’.* and *‘…couldn’t advise anything other than to stay home and self-isolate’.*

Of the 45.9% (n=17) people who said they did not receive the support they needed from health services, 12.8% (n=5) people cited misdiagnosis and 12.8% (n=5) people said they had been given conflicting or limited information. 10.2% (n=4) people said they had not beentaken seriously. For example, *‘I have been in and out of hospital and doctors with little to no help’.* and *‘They sent me home without testing me and just said it was “Anxiety” and “Anaemia”‘.* and *‘Advice was conflicting every time I spoke to a professional’.* and *‘All I received was information about reporting the situation to my employer and I was not offered a test’.* and *‘Often GPs not taking me seriously’.* and *‘We have been gaslighted by so many medical professionals’.*

In the focus group four out the seven people who participated said that GPs lacked knowledge of the condition or were unhelpful or condescending. For example, *‘In the early stage I just don't think they had a clue’.* and *‘When I came out [of hospital], I had absolutely nothing from the GPs. I never got a phone call’.* and *‘One of the GPs told me, "Well, you know why you got it, don't you…because you're fat.” I was like, "Well, actually in the hospital, he said it wasn't, and I'm not”‘.* and *‘One GP told me that he sprained his ankle and he just recovered at home. He basically implied that we should just shut up and recover at home like his sprained ankle’.*

While two out of the seven people who participated in the focus group said they had no support because they had not reached out for support, three people who sought out support said in part that it had been helpful, e.g., welfare calls from their GP or different parts of the NHS, but this was not consistent for everybody.

Two people who participated in the focus group said they were not initially believed but were later believed as more became known about the COVID-19 virus and they were able to get tested. They said that when they tested positive for COVID-19, attitudes changed, and they were taken more seriously and received some of the support they needed. One person had COVID-19 twice and was able to compare the symptoms and notice the attitude change.

For example, *'Because it wasn't a known thing, and I wasn't tested, I felt even family, people around me weren't really listening to what I was saying…even my husband said, "I think you're over-exaggerating here." Then when I actually had a positive test at the end of the year, I've got everybody apologizing, saying, "Yes, you did have it. You're exactly the same as you was first time"'.* and *'When I'd have the test confirmed, I'd got phone calls every other day asking me how I was, which I thought that was really supportive'.*

It is worth noting that referrals to specialist services had been delayed due to prioritisation of acute COVID-19 during the pandemic. This may have hindered the opportunity for GPs to refer people with Long COVID symptoms.

7.6% (n=3) people said they were given advice/psychological support and a recovery plan.

Question: Were you hospitalised for COVID-19?

Were you hospitalised for COVID?	Number	Percent
No	28	75.7%
Yes	8	21.6%
No answer	1	2.7%
Total	**37**	**100%**

Table number 5 - source all respondents (n=37)

Out of the 37 people who responded to our survey 75.7% (n=28) stated they had not been hospitalised for COVID-19, while 21.6% (n=8) were hospitalised with COVID-19. Only (2.7%) 1 person did not answer the question.

Question: If you were hospitalised, did you receive the care and support you needed?

If you were hospitalised, did you receive the care and support you needed?	Number	Percent
Yes	6	75.0%
No	2	25.0%
Total	8	100%

Table number 6 - source all respondents who were hospitalised (n=8)

Out of the 8 people hospitalised with COVID-19, 6 people were happy with the care they received in hospital. For example, *'From first diagnoses to discharge from hospital the staff were extremely helpful'.* Only two people were not happy with the care they received in hospital but only one person explained why. For example, *'I didn't feel I was supported. There was no warmth. I didn't feel they were concerned, not even offering me a drink of water or ask what I needed'.*

During the COVID-19 pandemic, precautions are taken to limit contact with COVID-19 patients to prevent the risk of contagion, which may have contributed to the patient feeling they did not receive the support they needed. In addition, staff were feeling time and emotional pressures during the COVID-19 response which may have hampered their ability to provide their usual support.

Question: What are the most frequent long COVID symptoms you are experiencing now?

What are the most frequent long COVID symptoms you are experiencing now	Number	Percent
Fatigue	34	91.9%
Brain fog	26	70.3%
Shortness of breath	25	67.6%
Achy limbs	20	54.0%
Headaches	23	62.1%
Dizziness	19	51.4%
Difficulty regulating temperature	14	37.8%
Cough	9	24.3%
Reduced appetite	8	21.6%
Hair loss	5	13.5%
Poor mobility/inability to exercise	4	10.8%
Existing condition	3	8.1%
Insomnia	2	5.4%
Increased heart rate	2	5.4%
Joint pain	2	5.4%
Rash	2	5.4%

Table number 7 – source all respondents who were hospitalised (n=8) Total percentages add up to more than 100% because some respondents gave multiple responses.

The most frequent symptom experienced by the 37 people who responded to our survey was fatigue 91.9% (n=34). Neurological and respiratory symptoms were also common with 70.3% (n=26) people stating they experienced brain fog and 67.6% (n=25) had shortness of breath, followed by 54% (n=20) people said they had achy limbs and 62.1% (n=23) people had headaches; 51.35% (n=19) people said they had dizziness; 37.8% (n=14) people said they had difficulty regulating temperature; 24.3% (n=9) people said they had a cough; 21.6% (n=8) people said they had reduced appetite; 13.5% (n=5) people said they had hair loss; 10.8% (n=4) said they had poor mobility/inability to exercise; 8.1% (n=3) people said they had existing conditions; 5.4% (n=2) people said they had insomnia; 5.4% (n=2) people said they had increased heart rate; 5.4% (n=2) people said they had joint pain and 5.4% (n=2) people said they had a rash. Other less reported symptoms were weight loss, difficulty swallowing and poor circulation with 1 person each stating these conditions.

For example, *'Quite extreme headaches. That's daily. Fatigue which is different to the chronic fatigue which I've had for years and years'.* and *'Intermittent cough…Especially if I talk for a while, I start coughing'.* and *'On bad days, weightiness and laboured breathing is all the time'* and *'Every so often I get shivers, and I've checked my temperature and it's absolutely fine'.* and *'I have had to give up working due to brain fog'.* and *'Increased heart rate when walking up hill extremely slowly or getting out of the bath. Rash'.* and *'I've still no smell or taste'.* and *'I have really bad pain in my legs all the time. It feels like every morning I ran a half marathon the day before'.* and *'Because I now get out of breath so quickly, it's impacted my ability to exercise, which in turn has meant I've put on weight, which has resulted in a decline in my emotional and mental health, not to mention my actual health'.*

Question: What support or follow-up support and care from the NHS and Social Services would be helpful to meet your needs?

What support from health and social care would be helpful to meet their needs?	Number	Percent
A long COVID clinic	28	75.7%
Information about long COVID	18	48.6%
Courses for pain/fatigue/symptoms management	17	45.9%
Peer to peer self-help support	15	40.5%
Online forum with health professionals (Question and answer session and information sharing)	12	32.4%
Helpline	12	32.4%
Professional support for emotional health and wellbeing	10	27.0%
Family support	9	24.3%
A referral	2	5.4%
Financial support	2	5.4%
Not answered	1	2.7%

Table number 8 – source all respondents (n=37) Total percentages add up to more than 100% because some respondents gave multiple responses.

Out of the 37 people who participated in our survey, 75.7% (n=28) said they would like to be seen and treated in a one stop Long COVID clinic as opposed to having many separate referrals. For example, *'If I knew that all I had to do was get a referral to one place, and they would manage my journey, then I will be much more likely to engage with it'.* and *'These long COVID clinics, unless they're interdisciplinary clinics where we can get tests for all the things, talk to all the specialists, and they can cut across their silos, then ultimately, the long COVID clinic is just the same as your GP making 1000 different referrals'.*

48.6% (n=18) people said they would like more information about Long COVID with 32.4% (n=12) people saying they wanted online forums provided by health professionals with question-and-answer sessions and information sharing. For example, *'I wish there was more knowledge and awareness of Long COVID'.* and *'I have had no real help from my GP or anybody else and have had to do my own research on the Internet and trial things for controlling the symptoms'.* and *'I asked my GP for advice which was a waste of time as I knew more than she did'.*

45.9% (n=17) people said they would like courses for managing pain/fatigue/symptoms. *'I attend a Zoom course for pain management. I wonder if there can be something similar for those of us to manage fatigue'.*

40.5% (n=15) people said they would like peer to peer support or self-help group, while 32.4% (n=12) people said they wanted a helpline. Some people, 27% (n=10) said they would like professional emotional and well-being support such as counselling, and 24.3% (n=9) people said they would like support for the family. For example, *'The whole ordeal has been traumatic, and I have been told I am suffering from PTSD and am awaiting CBT. I am so much more emotional than I was'.* and *'The emotional, social, psychological support…, when you live on your own, there's no one to talk to, and talking with other people who've had COVID could be so important to know that you're not on your own'.*

In the focus group, it was a concern for some people that long waiting lists for mental health support would mean people may have to pay for counselling or therapy, which may not be accessible to people who cannot afford the sessions but need them most.

For example, *'On the mental health, the people who are privileged enough to be able to pay will get help, most of them [therapists] cost 60 quid an hour. I really wonder what's going to happen for people who really need help, and who can't get it'.*

5.4% (n=2) people said they would like a referral and 5.4% (n=2) people said they would like financial support. 2.7% (n=1) did not answer the question).

Question: Has long COVID affected your emotional health and wellbeing, for example anxiety?

Has long COVID affected your emotional health and wellbeing?	Number	Percent
Yes	29	78.4%
No	7	18.9%
No response	1	2.7%
Total	**37**	**100%**

Table number 9 – source all respondents (n=37)

Question: If yes, please explain your answer

If yes, please explain your answer	Number	Percent
Anxiety	13	35.1%
Not believed	6	16.2%
Emotional	6	16.2%
Frustration	5	13.5%
Low mood/depressed	4	10.8%
Agoraphobic (fear in situation where escape might be difficult, or help would not be available if things go wrong)	4	10.8%
Fatigue/ exhaustion	3	8.1%
Anthropophobia (fear of social situations/meeting people)	3	8.1%
Trauma and PTSD	3	8.1%
Loss of confidence	3	8.1%
Decline in physical strength	3	8.1%
Loss of memory	3	8.1%
Somniphobia/ insomnia (Fear of going to sleep or difficulty sleeping)	3	8.1%
Lonely	2	5.4%
Scared	2	5.4%

Table number 10 – source all respondents (n=37)

Most people, 78.4% (n=29) said Long COVID had affected their emotional health and wellbeing, for example 35.1% (n=13) people said they had anxiety. 16.2 (n=6) people said they felt they were not believed, and 16.2 (n=6) said they were feeling emotional and frustrated. 10.8 (n=4) people said they had low mood or were feeling depressed, and 10.8 (n=4) people said they were fearful of going out or mixing with other people in case, they caught COVID-19 again. 8.1 (n=3) people said they had trauma and signs of Post-Traumatic Stress Disorder. The same number of people 8.1 (n=3) said they had a loss of confidence, decline in physical strength, loss of memory, fear of going to sleep or difficulty sleeping. 5.4% (n=2) people said they felt lonely and scared. For example, *'Feeling down and isolated. Tearful. Only sleep 4 hours a night. Afraid to go to sleep in case I don't wake up'.* and *'I have very bad health anxiety and I'm afraid to go out or go near anyone. I'm only 29 years old and my life is completely ruined. I need help'.* and *'I had a panic attack at the dentist and felt I couldn't swallow or breathe with tubes in my mouth and them in full PPE'.*

Only one person each (2.7%) said the following: *'cannot multitask'*, *'feel confused'*, *'fear of being awake'*, *'agitated by noise'*, *'pain'*, *'panic attacks'*, *'long term change to physical health'*, *'fear of stopping breathing'*, *'claustrophobia'*, *'survivor guilt'* and *'visual and auditory hallucinations*.

18.9% (n=7) people said Long COVID had not affected their emotional health and wellbeing.

2.7% (n=1) person did not answer the question.

Conclusions

Long COVID is a new, complex, and relatively unknown syndrome affecting a significant number of people in terms of their physical and mental health and well-being (possibly one third of those who had COVID-19). The purpose of the project was to find out the experiences of people with Long COVID and the response from health services in providing care and support to meet their health needs. It was also important to involve people with Long COVID as experts with lived experience in the questionnaire design, analysis and report writing as well as presenting recommendations to health commissioners and decision makers for future planning in healthcare delivery.

Out of the 37 respondents who took part in our online survey, just under half said they did receive the support they needed from services such as 111, GP or 999 when they first experienced COVID-19 symptoms. However, just under half said they did not receive the support they needed, with around 1 in 10 people citing misdiagnosis, getting conflicting or limited information, or not being taken seriously. In the focus group, over half said primary care providers, in particular GPs lacked knowledge of the condition or were unhelpful or condescending.

People who experience Long COVID symptoms are finding it frustrating to navigate the NHS system for appropriate treatment and care. From our survey, over a third of people reported that the main symptom they were experiencing was fatigue, while a quarter of people were experiencing brain fog and shortness of breath. One fifth of people reported achy limbs, headaches, and dizziness. Under one sixth of people reported difficulty regulating body temperature, while lesser reported symptoms including cough, reduced appetite, hair loss, poor mobility, insomnia, and rash. The Long COVID symptoms people experience not only make seeking appropriate care even more difficult, but also hinders them from carrying out normal everyday activities and impacts their quality of life.

Over three quarters of people in our survey said that Long COVID has impacted their mental health and well-being, with over a third of people saying they have anxiety and fear to go out or mix with people in case they catch COVID-19 again. Around one sixth of people felt they were not believed by primary care providers, while around 1 in 10 people were feeling emotional, frustrated, and depressed. This is due to the symptoms they are still experiencing; not receiving the treatment and care they need, and have not being able to do simple, normal everyday activities.

Three quarters of people in our survey said that a one stop Long COVID clinic for assessment and treatment would help meet their health needs as opposed to having many separate referrals. Currently only patients who were hospitalised with COVID receive treatment for respiratory conditions in the COVID clinic at the Queens Medical Centre. While there is a COVID assessment clinic being piloted for non-hospitalised patients via a GP referral, it is not a treatment clinic.

Just under half of the people surveyed said that more information is needed about Long COVID, with one third saying they would like online forums provided by health professionals with question-and-answer sessions and information sharing. Over half the people surveyed said they would like courses for managing pain/fatigue/symptoms.

Two fifths of the people surveyed said they would like peer to peer support or a self-help group, with one third of people saying they would like support by way of a helpline. A quarter of the people surveyed said they would like professional emotional and well-being support such as counselling or therapy, and support for the family.

Recommendations

HWNN recommends immediate attention to the following:

- Primary health care providers to have greater awareness and recognition of Long COVID, and to understand the range of symptoms; and be able to refer and signpost patients to relevant support to manage those varied symptoms.
- The Integrated Care System (ICS) and Clinical Commissioning Groups (CCG) to commission appropriate rehabilitation and treatment services including commissioning of a one stop Long COVID clinic offering treatment for numerous and varied symptoms so that access to services is not impacted by a fragmented care pathway.
- The ICS and CCG to review and commission appropriate mental health support e.g., peer-to-peer self-help support and helpline, and fast track to professional counselling, therapy and emotional health and wellbeing support.
- Community Healthcare Providers to enhance and promote their current offer for courses on pain/fatigue/symptoms management, Your Covid recovery programme (referral by Health Professional), online and pre-recorded courses.
- National level: NHS England and ICS to provide more information about Long COVID for patients via an online forum run by health professionals, with question-and-answer sessions and information sharing (See Appendix 1 for the Nottingham Recovery from COVID-19 Research Platform (NoRCoRP).

Appendix 1

Local and national health service support for people with Long COVID

Long COVID: the NHS plan for 2021/22 builds on the five-point plan which outlines 10 key next steps to be taken to support those suffering from long COVID. It is underpinned by a £100million investment, £30million of which will go towards an enhanced service for general practice to support long COVID care and enable consistent referrals. The remaining £70million will be used to expand other NHS long COVID services and establish 15 'paediatric hubs' to coordinate care for children and young people.

The plan also highlights the need for equity of access, outcomes, and experience in long COVID support, as well as committing to extending the Your COVID Recovery website, collecting and publishing data.

This plan builds on the five-point plan for Long COVID support outlined by NHS England and NHS Improvement last year, and takes the total investment the NHS has input into Long COVID support to £134million to ensure that all those with ongoing symptoms of COVID-19 get the care they need.

https://www.england.nhs.uk/coronavirus/publication/long-covid-the-nhs-plan-for-2021-22/

www.yourcovidrecovery.nhs.uk – a national website providing information and self-management tools to support people recovering from Long COVID

Psychological therapy/talking therapy services (also known as IAPT) are free NHS services to help people experiencing anxiety, stress, depression to better manage their mental health. They are working closely with local Post-COVID Syndrome Assessment Clinics to help patients with psychological symptoms. Services are self-referral and waiting times are approximately 3 weeks (as of April 2021).

Pilot Post-COVID Syndrome Assessment Clinics are now operating across Nottingham and Nottinghamshire (May 2019). City Care provide an assessment clinic for City patients and Nottinghamshire Healthcare Trust provide assessment clinics for county patients. These clinics are GP referral only and assess patients' mental, physical, and cognitive needs, mostly by telephone but can arrange face to face, if necessary, for those whose symptoms have been ongoing for 12 weeks. They will then hold discussions with specialist clinicians and co-ordinate care. This Long COVID assessment clinic is being piloted for six months.

A Post-COVID Respiratory Clinic at Nottingham University Hospitals Trust, is available for patients who were hospitalized and focuses only on managing and treating respiratory symptoms (Jan 2021).

NUH Long COVID Research

The Nottingham Recovery from COVID-19 Research Platform (NoRCoRP) brings together projects examining the impacts and lasting effects of COVID-19. It aims to translate findings from patients who are known to have contracted the virus into new approaches to treatment to support their recovery.

It also aims to provide new insights for the NHS and social care, enabling services to be more responsive to the long-term impact of caring for patients, some of whom seem to be at risk of developing longer term conditions because of COVID-19.

How they hope this study will help patients

Many patients are experiencing ongoing breathlessness, fatigue, cognitive and psychological symptoms because of COVID-19. NoRCoRP will investigate the potential conditions caused by COVID-19 and provide answers as to why some people are more at risk of developing these than other people. It will also determine the most effective ways to speed up recovery. For more details visit https://www.nuh.nhs.uk/norcorp/

Appendix 2: Demographics of respondents

District	Number	Percent
Nottingham City	9	24.3%
Mansfield	9	24.3%
Rushcliffe	5	13.5%
Gedling	4	10.8%
Ashfield	4	10.8%
Broxtowe	2	5.4%
Outside of Nottinghamshire	2	5.4%
Newark & Sherwood	1	2.7%
Bassetlaw	1	2.7%
Total	**37**	**100%**

Appendix 2: Table number 1 – source all respondents (n=37)

Age Groups	Number	Percent
25-34	2	5.4%
35-44	7	18.9%
45-54	9	24.3%
55-64	10	27.0%
65-74	7	18.9%
Not answered	2	5.4%
Total	**37**	**100%**

Appendix 2: Table number 2 – source all respondents (n=37)

Gender	Number	Percent
Female	29	78.4%
Male	6	16.2%
Not answered	2	5.4%
Total	**37**	**100%**

Appendix 2: Table number 3 – source all respondents (n=37)

Gender Same as Birth	Number	Percent
Yes	35	94.6%
Not answered	1	2.7%
Prefer not to say	1	2.7%
Total	**37**	**100%**

Appendix 2: Table number 4 - source all respondents (n=37)

Sexuality	Number	Percent
Heterosexual	24	64.9%
Not answered	7	18.9%
Homosexual - Lesbian	4	10.8%
Prefer not to say	1	2.7%
Bisexual	1	2.7%
Total	**37**	**100%**

Appendix 2: Table number 5 - source all respondents (n=37)

Ethnicity	Number	Percent
White	31	83.8%
Not answered	3	8.1%
Mixed/Multiple ethnic	1	2.7%
Black	1	2.7%
Prefer not to say	1	2.7%
Total	**37**	**100%**

Appendix 2: Table number 6 - source all respondents (n=37)

Religion	Number	Percent
Christian (all denominations)	15	40.5%
No religion	8	21.6%
Atheist	5	13.5%
Prefer not to say	4	10.8%
Not answered	2	5.4%
Other	1	2.7%
Muslim	1	2.7%
Jewish	1	2.7%
Total	**37**	**100%**

Appendix 2: Table number 7 - source all respondents (n=37)

Nationality	Number	Percent
British	29	78.4%
Not answered	6	16.2%
Italian	1	2.7%
US/UK	1	2.7%
Total	**37**	**100%**

Appendix 2: Table number 8 - source all respondents (n=37)

Main Language	Number	Percent
English	35	94.6%
Not answered	1	2.7%
Other	1	2.7%
Total	**37**	**100%**

Appendix 2: Table number 9 - source all respondents (n=37)

Are you a carer for anyone?	Number	Percent
No	29	78.4%
Yes	6	16.2%
Not answered	2	5.4%
Total	**37**	**100%**

Appendix 2: Table number 10 - source all respondents (n=37)

Are you cared for by anyone?	Number	Percent
No	27	73.0%
Yes	7	18.9%
Not answered	3	8.1%
Total	**37**	**100%**

Appendix 2: Table number 11 - source all respondents (n=37)

Pregnant/children <5 years old	Number	Percent
No	36	97.3%
Not answered	1	2.7%
Total	**37**	**100%**

Appendix 2: Table number 12 - source all respondents (n=37)

Employment Status	Number	Percent
Full time	15	40.5%
Retired	10	27.0%
Part time	7	18.9%
Unable to work	4	10.8%
Not answered	1	2.7%
Total	37	100%

Appendix 2: Table number 13 – source all respondents (n=37)

Illness/impairment	Number	Percent
A long-term health condition	13	33.3%
Physical impairment	4	10.3%
Mental health illness	4	10.3%
Hearing impairment	1	2.6%
Learning disability	2	5.1%
Visual impairment	1	2.6%
Prefer not to say	1	2.6%

Appendix 2: Table number 14 – source all respondents (n=37) per condition)

Note: this is the number of respondents who have identified per condition

Disability Count	Number	Percent
Number of respondents	17	43.6%

Appendix 2: Table number 15 - source all respondents (n=37)

Note: this is the number of respondents who indicated they had at least one disability/impairment

Acknowledgements

Healthwatch Nottingham and Nottinghamshire would like to thank the participants who made time to share their experiences as part of this project.

The Volunteer Researchers

Self Help UK

HWNN Volunteers and Partners

Healthwatch Nottingham & Nottinghamshire
Unit 1, Byron Business Centre,
Duke Street,
Hucknall,
Nottinghamshire,
NG15 7HP
Phone: 0115 956 5313
Web: www.hwnn.co.uk
Twitter: @_HWNN

We are a company registered in England and Wales.
Company Registration Number: 8407721
Registered Charity Number: 1159968

healthwatch
Nottingham & Nottinghamshire