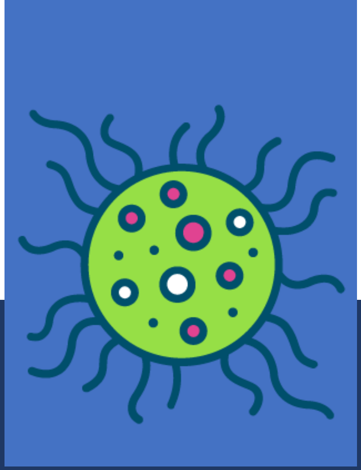


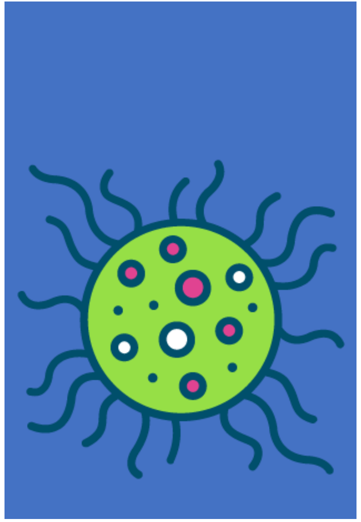
Healthwatch Kingston

Living with Long Covid report

Survey and Focus Group - July to September 2021

Published 28 February 2022

healthwatch
Kingston upon Thames



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1. About Healthwatch Kingston

Healthwatch Kingston upon Thames is your local health and social care champion. If you use GPs and hospitals, dentists, pharmacies, care homes or other support services in your area, we want to hear about your experiences. We are independent and have the power to make sure NHS leaders and other decision makers listen to local feedback and improve standards of care. We can also help you to find reliable and trustworthy information and advice. Last year, the Healthwatch network helped nearly a million people like you to have your say and get the support you need. Healthwatch Kingston upon Thames is part of a network of over 150 local Healthwatch across the country.

We're here to listen to the issues that really matter to people in the Royal Borough of Kingston upon Thames and to hear about your experiences of using local health and social care services. We're entirely independent and impartial, and anything you share with us is confidential.

Healthwatch uses your feedback to better understand the challenges facing the NHS and other care providers and we make sure your experiences improve health and care for everyone – locally and nationally. We can also help you to get the information and advice you need to make the right decisions for you and to get the support you deserve.

It's important that you share your experiences – whether good or bad, happy, or sad. If You've had a negative experience, it's easy to think there's no point in complaining, and that 'nothing ever changes'. Or, if you've had a great experience, that you 'wish you could say thank you'. Remember, your feedback is helping to improve people's lives. So, if you need advice, or you're ready to tell your story – we're here to listen.

2. Executive summary and recommendations

Between July and September 2021, Healthwatch Kingston undertook a community engagement project to gather the views of residents who were experiencing a complexity of symptoms associated with Long Covid (clinically named Post-Covid Syndrome). An online survey was co-produced by Healthwatch in SW London, with residents and other stakeholders and received responses from people experiencing symptoms of Long Covid, some of whom had formally been diagnosed, and some who had not had a formal diagnosis. Healthwatch Kingston also hosted a workshop about Long Covid and Mental Health on 22 September 2021.

The key findings from our survey concentrate on the respondents' lived experience of Long Covid, including diagnosis, symptoms, effects on livelihoods, relationships, family, and friendships, and includes their views on clinical and community support needs (met and unmet), and mental health challenges. Our findings resonate with other Long Covid evidence and with the suggestion that women are disproportionately impacted by Long Covid, outnumbering men by as much as four to one, with a higher risk of experiencing a range of debilitating ongoing symptoms after treatment for Covid-19.

The detrimental effects on both physical and mental health, everyday activities and lives were recurring themes shared, and the overwhelming need for improved, more seamless provision across clinical and other support services was evident.

Healthwatch Kingston 'Living with Long Covid' key recommendations:

1. **Create a comprehensive screening process** with seamless referral pathways to care and support.
2. **Ensure a multi-disciplinary team approach to care and support** based on needs, supported by education and training.
3. **Develop self-help support groups** (peer-led) inclusive of those that have missed an opportunity for a diagnosis
4. **Improve integrated and coordinated care and support** in the community, particularly post discharge from hospital.

3. Introduction

In the Autumn of 2020, during our 'Living with Long Covid' community engagement planning stages with local Healthwatch Kingston volunteers, we noted there was little local community evidence and wanted to understand if people's experiences reflected the needs identified in emergent literature. We also felt that due to the little anecdotal evidence we had heard locally about the symptoms of Long Covid, there was likely a need to approach care and support in a holistic 'joined-up' way. As a first step we were therefore keen to learn about the impact of Long Covid on local populations. What were people's experiences of access to care, the quality of the care they received, and their aftercare, what impact Long Covid was having on their lives and what would make a difference to them so that we could help better understand any unmet need?

There is now a rich body of evidence and broad knowledge on the symptoms and effects of Covid-19, but less is understood about the clinical outcomes, the duration and the management of the symptoms that occur following an initial infection - commonly known as Long Covid. Estimates for the number of people likely living with Long Covid vary greatly across different studies, from as little as 2.3% to as much as 37% of all individuals (ONS and Covid-19 Longitudinal Health and Wellbeing National Core Study, (2021) "Short Report on Long Covid") infected with Covid in the first place.

Long Covid is described as a complex condition which can present itself with multiple symptoms. Many experienced respiratory difficulties, coughs, sore throats, headaches, 'brain fog', joint pain, fatigue, persistent fever, loss of taste and smell. It can also affect organ systems in the body, which impacts detrimentally on the physical, mental health and everyday lives. Living with Long Covid is only made worse if uncertainty and a lack of understanding by some healthcare professionals is evident.

One Kingston survey respondent summarised their experience succinctly:

The last year has been traumatic. Having been a healthy and very active individual pre-Covid, contracting the virus has literally brought my life to a standstill.”

Also known as Post-Covid Syndrome, it is defined by the National Institute for Health and Care Excellence (NICE) as: ‘*signs and symptoms that develop during or following an infection consistent with Covid-19 which continue for more than 12 weeks and are not explained by an alternative diagnosis.’*. We understand that access to support for Long Covid proved challenging for some in earlier waves of the pandemic as symptoms associated with Long Covid only appeared after time.

The most effective ways to both treat and support those affected continue to be reviewed. Fluctuating symptoms are widely reported. Clinical tests are not always needed to diagnose Long Covid, but they may be used to rule out other causes of symptoms. Blood tests, chest x-rays, blood pressure and heart rate are some of the tests that may be requested. The lack of a definitive test means that Long Covid diagnosis is difficult for care professionals. This was particularly problematic for those with other pre-existing conditions. 16 out of 43 survey respondents said they had pre-existing conditions (37%) with similar symptoms to Long Covid, such as chronic fatigue syndrome.

I have been diagnosed with chronic fatigue, but symptoms are very similar to Long Covid.”

Living with Relapsing Remitting Multiple Sclerosis has made it tricky to distinguish the symptoms from potential Long Covid issues apart from loss of taste and smell and weird hair loss.”

I have an underlying gastro condition and since Covid it has been in a bad flare up, requiring weekly day unit visits at Kingston Hospital."

In March 2021, the National Institute for Health Research (NIHR) published its second themed review on 'Long Covid'. The NIHR report noted the following about the care and support needs of people living with Long Covid:

- *'Both people who have been discharged from hospital and those never admitted need health and social care support and rehabilitation as there is currently no 'cure'. As with all long-term conditions, this needs to go beyond the person with the symptoms to the family and carers and in a range of settings, including people's own homes and non-hospital residential settings. Consideration of how to provide this and the skills required to do so is an urgent priority and should include independent, third sector and voluntary providers who are already providing social support. This extends beyond healthcare and research questions need to include social impact (including the impact of moral judgements/stigma of having 'Long Covid') and returning to employment.'*
- *'Our [NIHR] steering group debated whether it [Long Covid] support needs to be a specialist service or part of all primary and community care services. Comparisons were drawn with the emergence of HIV in the 1980s and the arguments for and against specialist services. The contribution of different professions and their education about living with Covid-19 also needs to be studied to determine the optimal service and workforce configuration.'*
- *'The changing and multiple symptoms of ongoing Covid-19 are not well served by the way healthcare is currently organised. Covid-19 is a multisystem disease and people's experience echoes the challenges already experienced by people with multiple co-morbidities, who experience limited-service integration. As an example, one member of the steering group [NIHR] described a woman admitted to hospital for respiratory support who needed psychological*

support. Because of the way services are provided, mental health teams were unhappy about providing Post Traumatic Stress Disorder (PTSD) support in hospital and said she could self-refer once she had been discharged home.'

- *'The support needs of people who have been ill for long periods with any disease have been recognised for some time. One study found 64% of people who were treated in intensive care had problems with cognitive impairment, disability, or depression three months after discharge, and 56% still had problems at 12 months. Early in the pandemic there was an expectation that people who had been critically ill with Covid-19 and had extended stays in intensive care would need intensive rehabilitation. It is also apparent that they may have suffered long-term disabilities related to other events triggered by the seriousness of their illness … rather than by the virus itself and may therefore require specialised rehabilitation services related to the acuity of their illness rather than Covid-19 specifically.'*
- *'Whilst post-hospital care is important, the British Society of Rehabilitation Medicine notes there are people who were never admitted to hospital but who still have ongoing needs for rehabilitation support after recovering from Covid, or Covid-like symptoms. Indeed, we heard from people in our focus group who had been ventilated in critical care and received post-discharge rehabilitation care who said their ongoing needs are the same as those who had not received any hospital care, suggesting that care models need to be tailored specifically to Covid-19.'*

Healthwatch Kingston has since worked collaboratively with other Healthwatch and the NHS to find answers to these questions and has welcomed the clear appetite across health and social care stakeholders to ensure that local people's voices inform the development of the proposed aims (see page 9) of the Kingston and Richmond Long Covid service within the community.

Healthwatch Kingston provides this report to support these aims and will continue to gather Kingston residents' views and experiences of NHS and social care services, to ensure commissioners, providers and other system leaders respond appropriately to the health and care needs of local people.

Proposed aims for the Kingston and Richmond Long Covid service

Aim 1:

People with diagnosed or suspected Covid-19 have accessible information informing of what to expect when recovering from Covid-19, self-management advice to aid recovery, and sources of support locally and nationally.

Aim 2:

Improve access to assessment and support for people from underserved and vulnerable groups, who are experiencing new or ongoing symptoms after (suspected/diagnosed) acute Covid-19.

Aim 3:

Continued development of integrated and coordinated services across the Kingston and Richmond system, that provide timely, holistic, and person-centred support.

Aim 4:

All people requiring a community assessment will be assessed with a holistic and person-centred approach and have access to multidisciplinary input in a format appropriate to their needs.

Aim 5:

People with Long Covid will be supported with a focus on returning to their usual activities of daily living, with this being measured alongside symptom management with use of the Kingston Hospital Post C-19 Holistic Questionnaire.

Aim 6:

Assessment and support for deterioration of mental health should be prioritised for all people experiencing Long Covid symptoms.

(Provided by the Kingston and Richmond Post-Covid Steering Group)

3.1 Scope of this community engagement

Healthwatch Kingston agreed to work in partnership with Healthwatch Richmond, Merton, Sutton, Wandsworth, and Croydon across South West London to collect people's experiences in a similar timeframe and with a similar methodology. This allowed us to collect compatible and comparable data across South West London, to comprehensively inform support services within this area. We collected data about people's experiences of the illness itself, including symptoms and recovery, but also regarding the effects it had on their livelihoods and mental health. We asked people about the support they had received, if any, and about their unmet needs. The survey and a range of other Long Covid resources used during our planning of this community engagement can be found in the Appendices at the end of this report.

4. Methodology

To build a greater understanding of the impact of Long Covid on our local populations, Healthwatch Kingston, in partnership with neighbouring South West London Healthwatch, undertook local online surveys to gather the experiences of those affected by Long Covid, and to explore the variety of needs identified by them.

Kingston respondents were asked to complete the survey online and to add any further comments on their experiences of managing Long Covid, including their experience of the medical and community support services. We offered respondents the possibility to contact us by email, phone, or post for a more personal interview, should they be more comfortable doing so. The survey was built in concordance with input from the Kingston and Richmond Post-Covid steering group, and in concordance with Healthwatch across South West London. The latter agreed to each have a different survey, which would include a common spine of unchanged questions. This allowed each Healthwatch to integrate a more specialised focus to their own survey, while still collecting compatible and comparable data across the six boroughs.

In the Royal Borough of Kingston upon Thames, we communicated the online survey through multiple platforms, including our Healthwatch Kingston e-newsletter and social media, and through partner organisations in the borough. The respiratory department at Kingston Hospital, which hosts an acute care Long Covid service, kindly shared the survey with their patients, the South West London Clinical Commissioning Group (CCG) included a link to it on their webpage on Long Covid and Kingston Council and Kingston Voluntary Action published it in their newsletters.

We received 43 responses to our Kingston survey, of which 34 were from Kingston, 4 from Richmond, 2 from Sutton, 1 from Wandsworth, and 2 from outside of SW London boroughs (although bordering). Healthwatch Kingston also hosted an online community conversation about Long Covid and Mental Health on 22 September where ten local people shared their experiences.

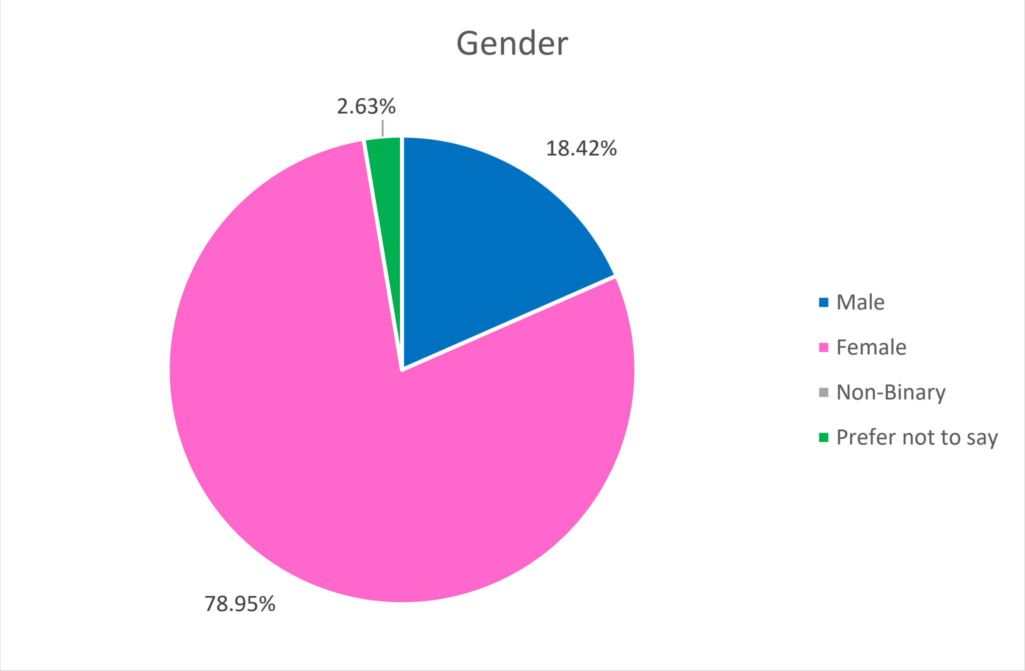
4.1 Limitations

We recognise the methodological limitations in online surveys and recognise that 43 respondents is lower than we would have wanted to participate. However, it is widely acknowledged that surveys are a useful tool in gathering information in a timely fashion and provide us with a snap shot of views and experiences at the time of the community engagement. Accessing the target group was a challenge, and we would have liked to have the opportunity to reach more people, including those who are digitally excluded. We were delighted by the efforts and depth of responses where people offered a range of views and experiences which adds to our local understanding.

We made the decision to mainly collect data online as it allowed us to reach people during a period of uncertainty and where few in person activities were running; we however urged our partner organisations to talk to their service users that may not use the internet and encourage them to contact us by phone instead. We also mentioned our work on Long Covid and the possibility to talk to us directly every time we did outreach events, including face-to-face.

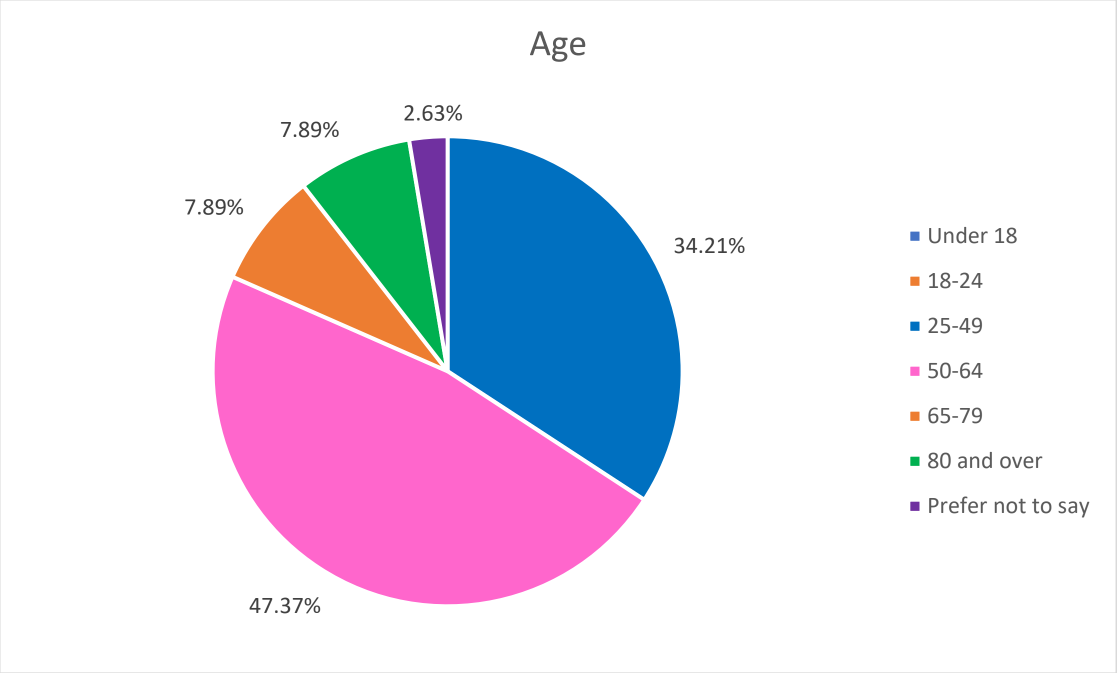
4.2 Demographics

Only 38 people out of the 43 responded to the questions on gender, age, ethnicity, and previous long-term conditions.



Similarly, to Healthwatch Richmond's Living with Long Covid survey results, far more women than men responded to our Long Covid survey, with nearly 80% female (30), nearly 19% male (7), 1 person preferring not to say and 5 skipped this question.

Women tend to be more likely to participate in online surveys (Smith 2009, 'Does Gender Influence Online Survey Participation?'), but this response is in line with evidence that women living with Long Covid outnumber men by as much as four to one. This pattern has also been seen in other post-infectious syndromes (ME/CFS in women and men (meresearch.org.uk)



Most respondents were of working age, (just over 80% aged 25-64), nearly 8% aged 65-79, and nearly 8% over 80 years of age. Only one respondent declined an answer. There were no responses from anyone under 25. This can be a limitation of an online survey, but it also consistent with the age groups of people likely to suffer more acutely from Covid-19 in the first instance (Covid-19: Middle aged women face greater risk of debilitating long-term symptoms | The BMJ).

To help reduce health inequalities, Healthwatch Kingston has committed to 'moving towards' better representation in our engagement work and is promoting a collaborative approach with voluntary sector organisations and with support from local community champions.

Respondents mainly identified as White British (nearly 74%, 28 people), with nearly 8% as White European (3), 1 person identified as White Irish, and 4 people identified as having a White background. There were no responses from Black British, and only 2 identified as Asian (one as British Asian, and one as other Asian). 2 people identified as other mixed, multiple ethnic background.

We know from national research that people from black, Asian, and ethnic minorities (BAME) in the UK have been disproportionately affected by Covid-19. National Institute for Health Research (NIHR) research suggests that during the first wave of Covid-19 people from BAME communities were twice as likely to be infected, and at significantly greater risk of dying due to the virus compared with people from a White ethnic background. Although our survey sample size is small, it suggests our Long Covid response rate reflects one of the top line findings in the ONS 'Short Report on Long Covid' (July 2021), that non-white ethnic minority groups are less likely to report Long Covid.

5. Long Covid services in Kingston

The development of Long Covid services for the people of Kingston has been led by a Kingston and Richmond steering group, chaired by Kingston GP, Dr Annette Pautz. Over the last year, the group, made up of a team of multidisciplinary health and care professionals, has developed a number of services for local residents. Your Healthcare have been providing therapies for people in the local community with more complex patients having access to a specialist clinic at Kingston Hospital with support also from the local iCope psychological therapy service and adult social care services. People can access the services through their own GP.

These services are designed to address symptoms including breathlessness, fatigue, and brain fog, commonly experienced by people suffering from Long Covid. Residents can also access online support provided by local and national voluntary organisations and other professional bodies.

For more information, visit: Long Covid recovery - South West London Health and Care Partnership (swlondon.nhs.uk)

6. Key findings

Data from the UK Covid Symptom Study app suggests that while most people recover from Covid-19 within two weeks, one in ten people may still have symptoms beyond three weeks, and a smaller proportion for months. This section of our report is based on the experiences shared by local people with Healthwatch Kingston. It provides feedback about what living with Long Covid has been like for respondents. It covers their initial diagnosis, what their symptoms were like, the impact on their lives, and their support needs.

6.1 Experiences of Covid-19 diagnosis

When we asked people if they received a positive diagnosis for Covid-19 before being diagnosed with Long Covid or experiencing Long Covid symptoms. 16 said “no” and 26 said “yes” with 1 person saying they had Covid before tests were available. In addition, we asked people how or where their diagnosis was confirmed. Responses varied as follows: antibody test (7 people); home test kit (6); testing centre (5); PCR test (4); hospital (2); drive through (2).

Me and my children had PCR's that tested negative however, their symptoms persisted and several days later we all tested positive with a Lateral Flow (home testing kit).”

Mine was negative as I was on day 12 of symptoms but my husband’s test was positive. However, I did get a positive antibody test in May 2020.”

6.2 Experience of Long Covid diagnosis

We then asked people if they received a Long Covid diagnosis for Covid. 18 (44%) said “yes”, 20 (49%) shared they had “experienced symptoms”, 2 people skipped this question. Three respondents to this question said “other” (7%) and this is what they said:

I have been suffering with Long Covid since March 2020. Have never been officially diagnosed with Long Covid but have been treated under the banner ‘suspected’ Covid. Testing was not available in March 2020 in the local community.

I have been diagnosed with chronic fatigue, but symptoms are very similar to Long Covid.

Awaiting diagnosis from GP, awaiting blood and x-ray results and follow up with GP next week. I am experiencing chest pain, shortness of breath and extreme tiredness. I experienced brain fog for 3-4 months after testing positive and felt like I had forgotten things I once knew how to do, especially at work, however this has improved a bit. I struggle to get to sleep with chest pain. I am exhausted and found myself sleeping a lot and falling asleep during the daytime which is unusual for me (pre-Covid).

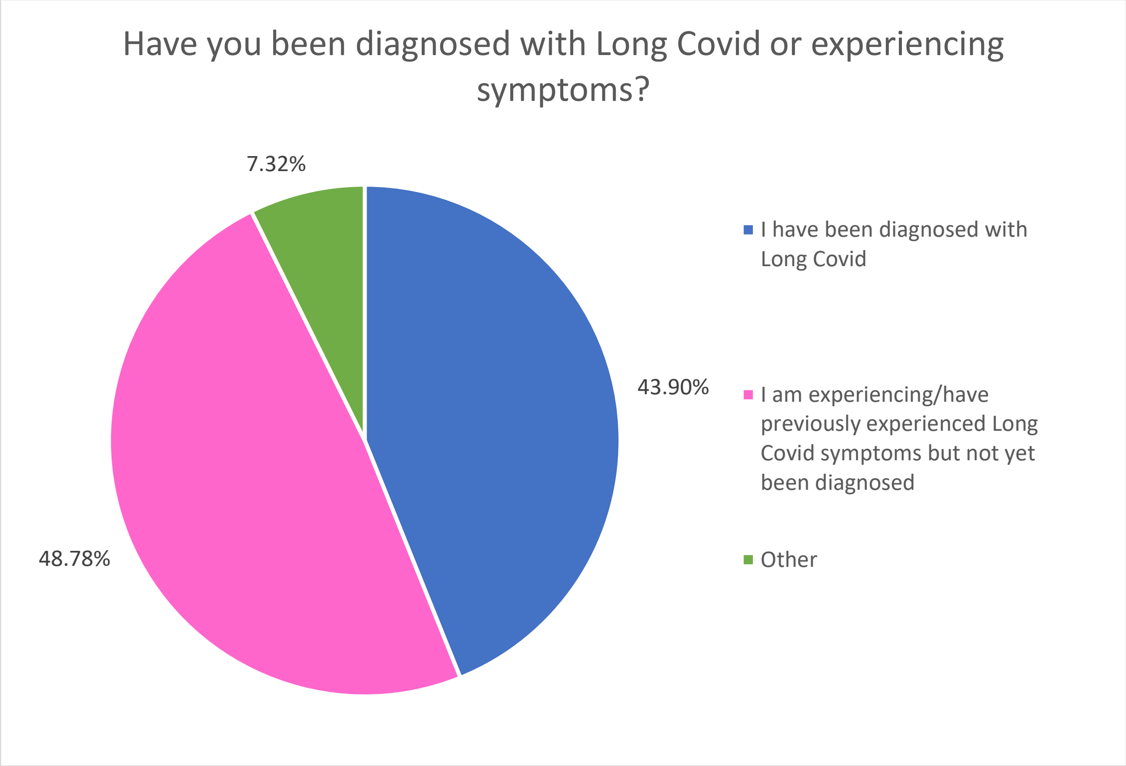
In addition, we asked people if they have been diagnosed, or are waiting to be diagnosed to tell us more about their experience. As responses to this question were rich and informative, we have provided all of these in the Appendices (from page 43) at the end of this report. Here is a selection:

Chest x-rays and blood tests revealed nothing abnormal. A telephone assessment by the Long Covid clinic at Kingston Hospital then referred me to an online Active Breathing Course.”

I caught Covid in March 2020. At the time, getting a test was near impossible but my husband bought 2 for us. I was day 12 of symptoms and mine came back negative but my husband was on day 5 and his was positive. Since then, I have suffered with extreme fatigue, brain fog, change to my taste and I keep getting infections (tooth with removal, sinus, fingers). It wasn’t until January 2021, when I was being prescribed course number 10 of antibiotics, that my GP said it could be Long Covid and sent me for blood tests. I was then told I'd be referred to a Long Covid clinic and got a chest scan and ECG in March 2021.”

I got Covid in Spring 2020. I thought I was better and then experienced really bad respiratory issues. Waking up in the night gasping for air and having to take an inhaler, not being able to sleep without vapour rub on my chest and having to sleep sitting up. I would get tired from the shortest walk and had to sleep lots but found sleeping really hard due to not being able to sleep lying down. Doctors did lots of tests and could see my lungs were very inflamed. At first I was told it was anxiety but then they linked it to Covid.”

As acknowledged in our introduction, the diagnosis of Long Covid is difficult to identify and treat, not least because people presenting may have had other health conditions, and these would need to have been eliminated as a possible explanation prior to a formal Long Covid diagnosis. Our survey results clearly indicate a considerable amount of unmet need in the community, as the majority of respondents experiencing Long Covid symptoms have not yet been diagnosed (49%).



We recognise that Long Covid (Post-Covid Syndrome) was not recognised as an ongoing condition until well into the coronavirus pandemic, but there was a common theme amongst our respondents, that there were long waiting lists to get a diagnosis.

Another Kingston survey respondent however, shared an example of rapid access to care:

> *After suffering with Covid in the summer and many of my symptoms not improving I called the GP last week. After a 30 min wait to talk to the receptionist all appointments were taken. When I explained my symptoms and told them I thought I may have Long Covid they found me an appointment later that afternoon. The Doctor was very helpful and immediately referred me to the hospital for further investigation. Blood tests, chest x-rays and are going to investigate my palpitations.”*

6.3 Symptoms

Based on research studies and patient surveys, over 200 symptoms of Long Covid have been reported to date. One Kingston respondent shared an extensive list of symptoms they had experienced:

> *Internal body tremors/sensitive teeth/stabbing pains in armpits/itchy armpits/hallucinations/Pins and needles and numbness in hands/Joint pains/swollen painful veins in lower arms and hands/tinnitus and ongoing earache in right ear/heart palpitations/fizzing blood sensation throughout body/loss of voice/hoarse voice/dry tongue/steely taste in my mouth/chills and hot flushing/conjunctivitis/dizzy spells/light headedness/jaw fatigue whilst eating.”*

Our survey included a grid question, with 12 of the most reported symptoms for which respondents could indicate the severity. The options were ‘Never experienced/got better within twelve weeks’, ‘MILD - did not stop me doing anything’, ‘MODERATE - made it difficult to do something’, and ‘SEVERE - made it difficult or impossible to do something’.

Table A - How 40 people (=100%) reported the severity of their symptoms (3 people skipped this question):

Symptoms	MILD		MODERATE		SEVERE		Total	
Breathlessness	15%	6	50%	20	27.5%	11	**37**	**92.5%**
Fatigue	5%	2	45%	18	42.5%	17	**37**	**92.5%**
Muscle pain	20%	8	32.5%	13	15%	6	27	67.5%
Fever	20%	8	7.5%	3	7.5%	3	14	35%
Anosmia	20%	8	17.5%	7	12.5%	5	20	50%
Brain fog	25%	10	40%	16	27.5%	11	**37**	**92.5%**
Anxiety	15%	6	32.5%	13	27.5%	11	30	75%
Heart (Chest tightness and/or palpitations)	17.5%	7	35%	14	17.5%	7	28	70%
Headache	20%	8	37.5%	11	17.5%	7	26	75%
Insomnia	22.5%	9	25%	10	22.5%	9	28	70%
Rashes / skin	12.5%	5	12.5%	5	0%	0	10	25%
Memory loss	25%	10	25%	10	12.5%	5	25	62.5%
Other symptoms	**5%**	**2**	**10%**	**4**	**5%**	**2**	**8**	**20%**

‘Brain fog’, ‘fatigue’ and ‘breathlessness’ were the most highly reported symptoms (highlighted in pink in table A, page 20).

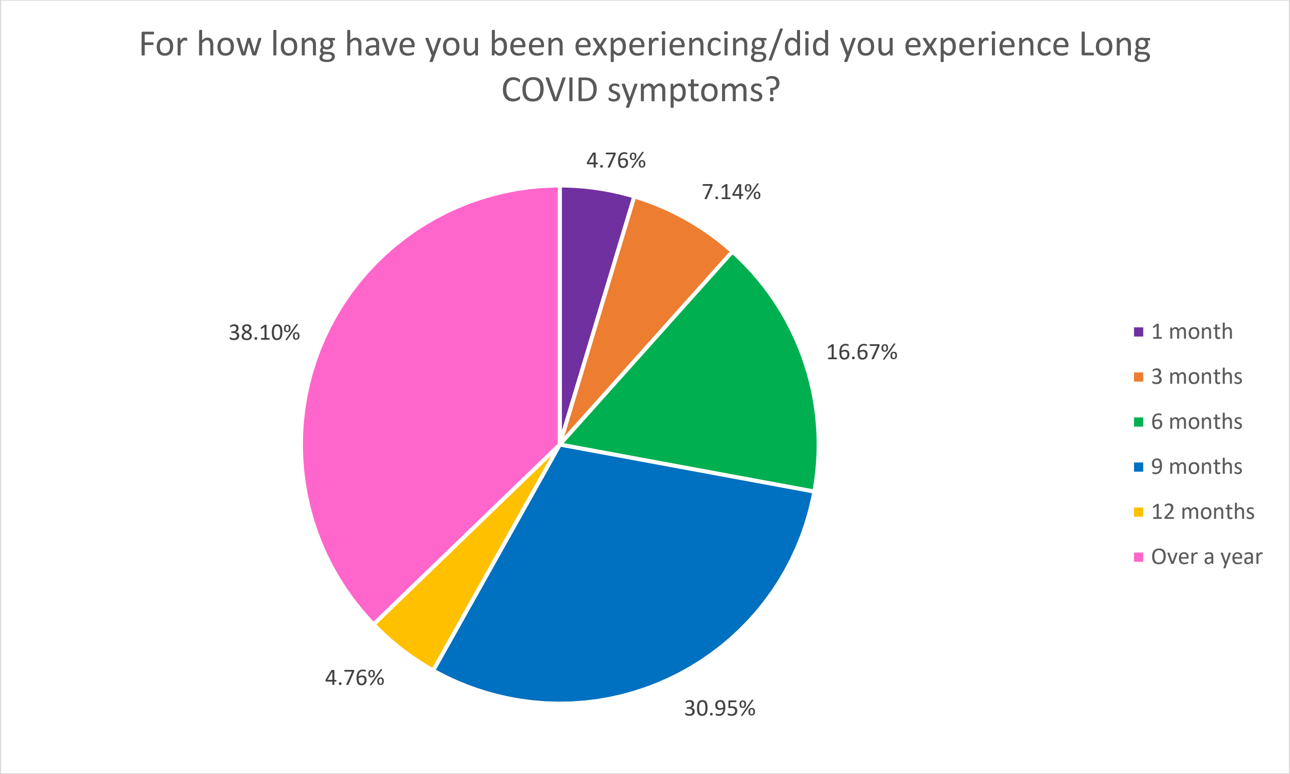
The next group of most experienced symptoms (highlighted in blue in table A, page 20) were: ‘anxiety’ (30 people experienced either mild, moderate, or severe anxiety), ‘heart’ and ‘insomnia’ (28 people each), ‘muscle pain’ (27), and ‘headache’ (26).

‘Brain fog’ and ‘memory loss’ were the two highest reported ‘mild’ symptoms. ‘Breathlessness’, ‘fatigue’ and ‘brain fog’ were the highest reported ‘moderate’ symptoms and, ‘fatigue’, ‘breathlessness’, ‘brain fog’ and ‘anxiety’ were the most reported ‘severe’ symptoms.

We asked respondents to share ‘other symptoms’ they had experienced, and this is a selection of what people said:
Acid reflux, nausea, bad taste in mouth or no taste, fake or bad smells, tinnitus, labyrinthitis, dizziness, loss of voice, palpitations, sleep paralysis, joint pain, pins and needles, body tremors, itchy skin and hair loss.

The NHS states that recovery from Covid-19 is different for everybody: *‘Many people feel better in a few days or weeks, and most will make a full recovery within 12 weeks. But for some people, symptoms can last longer. The chances of having long-term symptoms do not seem to be linked to how ill you are when you first get Covid-19. People who had mild symptoms at first can still have long-term problems.’*

In the context of the NICE definition of Long Covid: *‘signs and symptoms that develop during or following an infection consistent with Covid-19 which continue for more than 12 weeks*’, survey respondents were asked how long they have been experiencing Long Covid symptoms? 81% (38 people) said they had been experiencing symptoms of Long Covid for 6 months and over, 38% (16 people) of these stating that they had symptoms for over a year.



The qualitative responses to our Kingston survey indicate high levels of physiological illness, fear, and concern, including an inability to function in everyday life. This is of major concern to both patients and clinicians alike and will certainly impact on services in the future. Some of the more complex symptom experiences included:

In the initial stages of Covid I had pleurisy and labyrinthitis. The pleurisy was treated with steroids and antibiotics (as this combination has worked for me in the past). However, the labyrinthitis is still present. Unfortunately, I am unable to take the medication prescribed (Prochlorperazine). The medication makes me disorientated and very sleepy, and as I am already experiencing fatigue and severe brain fog, they were affecting my ability to look after my children. As a single parent with a disabled mother there is no one to support me while my body adapts to new medication, and I must be able to function to take care of my family. This means I'm still struggling with balance, dizziness, and sickness. I have also been struggling with a prolonged episode of fibro since falling sick with Covid, and palpitations are making it difficult to sleep."

A croaky voice especially when on the telephone. No longer able to sing. Occasional bouts of severe coughing. After recovery I felt cold for six months. Occasional bouts of fatigue"

Sleep paralysis - never have had this in my life - it's been traumatic. I would be waking up gasping for air and screaming and then would take an inhaler and be able to breathe again. After the vaccine I had to go to A&E as my legs swelled up. I now have sharp pains in my legs a lot."

6.4 Changes in symptoms

Table B - How Long Covid symptoms changed since people started experiencing them? This is how 40 people responded:

Symptoms	Improving		Worsening		Fluctuating		No change	
Breathlessness	**35%**	**14**	2.5%	1	37.5%	15	7.5%	3
Fatigue	20%	8	20%	8	30%	12	15%	6
Muscle pain	**30%**	**12**	7.5%	3	22.5%	9	10%	4
Fever	17.5%	7	0%	0	5%	2	2.5%	1
Anosmia	20%	8	2.5%	1	12.5%	5	12.5%	5
Brain fog	27.5%	11	7.5%	3	27.5%	11	20%	8
Anxiety	25%	10	15%	6	25%	10	15%	6
Heart (Chest tightness and/or palpitations)	**37.5%**	**15**	7.5%	3	25%	10	0%	0
Headache	27.5%	11	7.5%	3	20%	8	5%	2
Insomnia	12.5%	5	12.5%	5	27.5%	11	10%	4
Rashes	10%	4	2.5%	1	7.5%	3	5%	2
Memory loss	27.5%	11	12.5%	5	12.5%	5	10%	4

As anticipated, respondents reported changes in symptoms over time, with some stating that the challenges associated with changes in their symptoms increased their anxiety. People also reported most improvement (highlighted in green in table B, page 24) in terms of breathlessness (35%), muscle pain (30%) and chest conditions (37.5%). In addition, the Kingston data indicates that people were experiencing prolonged fatigue, anxiety, brain fog and insomnia (highlighted pink, table B, page 24).

Based on the equivalent data provided in the Healthwatch Richmond report, our Kingston survey responses suggest that fewer people have seen improvements in their Long Covid symptoms than in Richmond. On average, 24% of respondents indicated that their symptoms have been improving (compared to 39% in Richmond), an average of 21% said that symptoms have been fluctuating, less than in Richmond (35%), an average of 10% said that they have remained the same (this was 19% in Richmond), and an average of 8.5% said that their symptoms have been worsening, which is slightly more than in Richmond (7%).

“*My symptoms have changed since my initial stages of Covid, now I'm just so tired all the time and sleep isn't helping. The brain fog has now triggered my anxiety as I'm constantly forgetting things. It’s affecting my work and my ability to look after my family.”*

“*So,16 months on my symptoms have much improved but I am still suffering with random bouts of a mixture of symptoms off and on. These are not as severe as during the first 10 months but continue to occur randomly. Over exertion still brings on fatigue which requires resting up. Pacing is still very important. Climbing stairs still raises my heart rate and causes short term breathlessness. Tinnitus is constant. Sinus headaches are managed by sticking to a low histamine diet. Internal tremors are still prevalent. Forgetfulness is still a problem.”*

My whole personality has changed. I was active but now everything is an effort. The memory loss is short term, so having been given training at work I struggle to retain it. My anxiety has increased because of the awareness of this. I used to be a morning person but struggle to get motivated and out of bed. I feel more tired as time goes on."

Unsurprisingly, survey responses, indicate a range of different symptoms and recovery times. More work is required to disentangle the complexity of Long Covid symptoms, and the changes people experience so that appropriate support needs are identified to support recovery.

6.5 Impact on everyday life (including work, friendships, and relationships)

It is evident that people are struggling with the symptoms of Long Covid, that the length of time differs for everyone, but the experience is both life changing and impacts detrimentally. The quality of people's lives is impaired and they struggle to maintain everyday tasks and meet both family and professional responsibilities.

The following selection of responses from our Kingston survey illustrates both the personal and professional impact of Long Covid, and shows how ongoing symptoms exacerbate people's ability to function:

I am giving up my allotment because I've lost my strength and enthusiasm. My family are great, but widespread. Fortunately, my youngest lives at home and helps."

“I am exhausted much of the time, so finishing paperwork and managing my caseload effectively has been a challenge alongside keeping up with managing a household and work/life balance. Keeping up with workload means I spend more time working but get less done than I used to because I am exhausted. I also find visiting homes difficult, by the time I climb steps, even one level, I am breathless and have chest pain, and I’m sweating. I struggled to get to sleep with chest pain which felt very physical/muscle type pain at the beginning, and not sleeping well has impacted on my ability to work and my work performance.”

“My work life has become more demanding, due to its nature, but I struggle to remember things, I have to keep notes all the time which I didn't before, it was within my ability to recall procedures.”

“It has had a huge impact on my way of life. I am normally quite active, but now find most physical chores overwhelming. Breathlessness interferes with all social interaction. I am tired all the time, I forget things - which is not like me at all - I get confused; I am fed up with being like this. I thought I was improving regarding breathlessness, then I had a heart procedure a month ago and am back to bad breathlessness again. Also, my heart responded very differently to this routine procedure, which I've had twice before with no problems - this time I had pericarditis which was incredibly painful and very disabling.”

It has greatly impacted my life. I have had to reduce my working hours and even doing less it is hard to perform my duties at home. Looking after my son has been harder and often, I cannot play with him and only give him the basic care he needs. I am trapped in the house more and feel much more vulnerable to getting ill again as this has led to relapses and worsening symptoms. I don't think people take seriously the risk of Long Covid now restrictions have lifted. I can hardly exercise or go anywhere without the fatigue worsening and even though I am out of bed, I must think of ways to preserve energy. It's a very debilitating condition. I can probably do a third of what I used to be able to manage and I still need to rest a lot and have frequent fatigue crashes."

It's awful but no one understands, the worst thing is loss of taste and smell as I'm a keen cook."

Long Covid has hugely impacted my life, my ability to care for family as I'm so tired, it's like there has been an energy vacuum. The simplest of things like housework or cooking a meal can mean I need to sit down and recover afterwards. As a single parent the little people depend on me to look after them, and as a part-time carer for my disabled mother, she relies on my care for her, I'm the only respite for my Dad. I have my Mum so he can go to work. Unfortunately, the Fibro is now such a problem I'm struggling to push her wheelchair. Feels like we are all trapped in my living room as I don't have the ability to take them anywhere else. And I don't have the time to rest and recover."

“The brain fog and problems with my memory is massively impacting my work, I'm struggling to hold on to conversations and can’t remember basic tasks. Without making very detailed 'To Do' lists I keep forgetting important deadlines. I feel like I'm putting pressure on the rest of the team and underperforming. The result is constant worry and working longer hours trying to make up for anything I've missed. I'm frustrated and exhausted and don't know how much longer I can carry on pushing myself like this.”

“Long Covid has ruined my life.”

More specific responses of the impact on friendships and relationships included:

“As for friendships and relationships with family, Long Covid has been incredibly isolating. I am not well enough to get out of the house often and recently I have had incredibly bad brain fog and headaches brought on whenever I do any cognitive activity. So, I haven't been able to message anyone. So, nobody can really understand what my illness is like for me. Even my family, who I manage to speak to regularly, don't really understand what it is like. I'm not sure I would if I wasn't experiencing it myself. I never knew how debilitating fatigue could be before now. Some days all I can manage is to get showered and dressed and have to spend the rest of the day lying down and listening to podcasts with my eyes shut. I used to be a very active person, always on the go.”

“It feels like Long Covid has taken all the joy out of my life. I am trying to adapt and find new interests and hobbies, but I am not able to be the person I was before. It has robbed me of my social life, my independence, my purpose, my career, my creativity.”

“I am lucky that I have a very supportive partner, but he has had to take on the role of carer and I am very reliant on him. I was the main breadwinner, so my illness has put pressure on him financially too.”

Balancing work and family life has proven to be challenging for many respondents, with relationships under strain, not least because of financial challenges. Some described having to leave jobs due to their symptoms, with others describing how difficult it was to juggle family and professional responsibilities. Simple tasks became difficult, exercise impossible and in some cases, the lack of energy and brain fog made it difficult to play, work or simply function as they used to before being impacted by Long Covid.

It is evident from these detailed and emotional responses that the experience of living with the symptoms of Long Covid has had a dramatic and detrimental impact on the physical and mental health of survey respondent’s lives.

6.6 Impact on mental health

Healthwatch Richmond reported that 78% of respondents to their Long Covid survey, felt that Long Covid had negatively impacted on their mental health compared with 85% of respondents (33/43) to the Healthwatch Kingston survey. Building upon what people told us about the impact of Long Covid symptoms and its detrimental impact on people's quality of life, common themes described by respondents relating to their mental health included: Isolation, social anxiety, fear, depression, stress, mood swings, panic attacks, fear of re-infection and low self-esteem. Here is a selection of what Kingston respondents shared:

It's very hard not to be able to do the things that you want to because of fatigue. The pandemic already made me more anxious but now I must be very protective of myself in order not to get ill again and relapse. It has been hard on my son's mental health too and in turn supporting him has been more challenging. I reach a sense of being overwhelmed far more quickly particularly as my brain fog has made it harder to do things that wouldn't have challenged me before. Being able to do so little is incredibly isolating."

I was always a glass half full type, now I often think, what's the point."

My mood isn't great because I am so physically incapacitated, so I get very fed up with the situation I am in. I also realise that I worry about getting ill again, with any respiratory virus, as I feel very compromised by my experience of Covid and Long Covid."

“The stress and worry of trying to care for other people when you are in pain and fatigued is exhausting. I'm not sure if the palpitations are caused by the virus, the medication, or the anxiety. Or has the anxiety and medication caused the palpitations. Feeling like you have constantly let other people down cripples your self-esteem. When you're the support network for other people, you have nowhere to turn for support for yourself.”

“I struggle to keep up with housework. I struggle to keep up with my work. An untidy home leads to stress and conflict with my partner. Feeling exhausted which has resulted in getting less work done in the same amount of time I used to be able to get it done, I am spending more time on work but getting less done, causing issues with my performance at work and this in turn has led to stress and anxiety about keeping my job. I feel old. Because I wasn't keeping up with my work, I felt I was letting my team down and I was being lazy, which impacted my self-esteem and mood.”

“Mentally this has been challenging, upsetting and anxiety inducing. Physically there are things happening with my body and the fear of what the long-term implications might be are distressing. My wellbeing overall has been greatly affected.”

The impact on our respondent’s mental health is clearly a core challenge for people experiencing Long Covid symptoms. At a time when all services are under pressure, careful consideration is needed about how to support these needs in the community. This will require careful planning and should be accounted for in future commissioning plans and service development.

6.7 Support needs

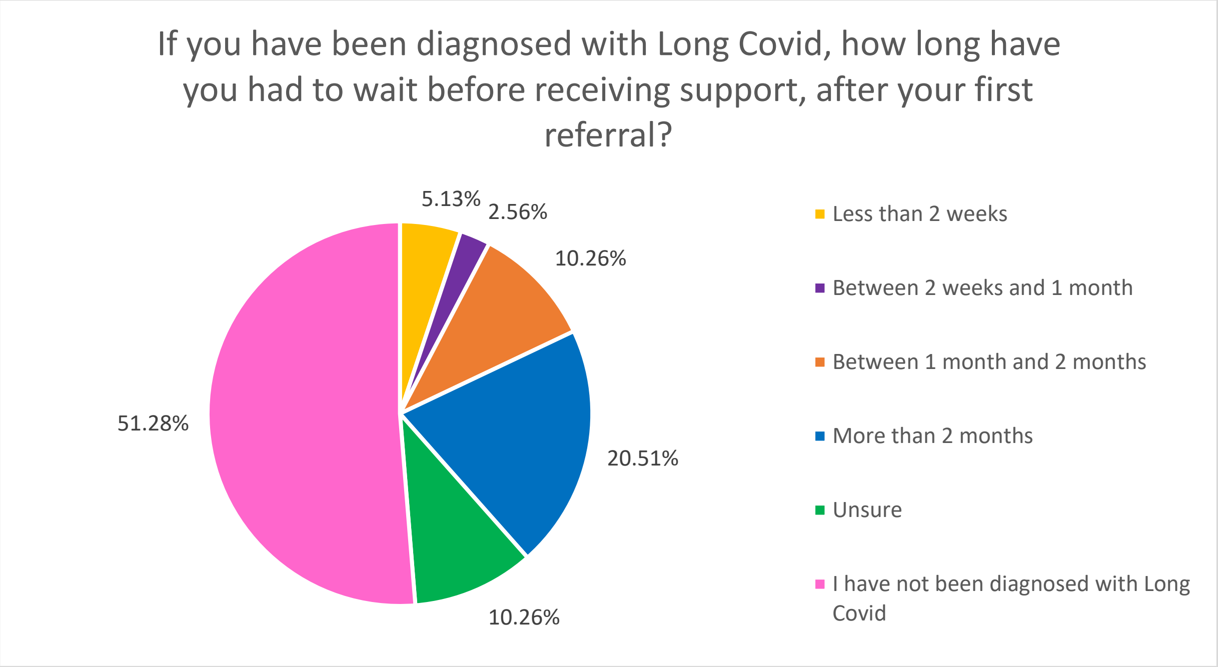
It was evident from the Kingston survey responses that people differentiated between their clinical support needs and their more community and social care needs, including the need for mental health and wellbeing support.

Support came from a range of sources but the journey for patients mainly began with their GPs who then put them in touch with a variety of specialist provision. These included a referral to the Long Covid Clinics at St Helier Hospital where the respondent was then referred on to the Epsom Hospital Chronic Fatigue Clinic, and also several referrals to the Kingston Hospital Respiratory Clinic. Some people, however, reported issues with referrals from their GP such as:

> *In early March [2020] I asked my ex-GP surgery for a referral to a Long Covid Clinic but was told that the surgery was unable to refer patients into these clinics."*

29 out of 33 people that replied to a question about access to community care stated that they either had no access or did not need it. One of the four that had received community support said the voluntary sector offer of support was comforting, but not needed. Another mentioned they had taken a breathing course with 'Voices for Hope' which was excellent and two said that they had accessed Cognitive Behavioural Therapy via Kingston iCope service, one adding the course was useful but too short.

The chart below shows that 8 people (21%) reported waiting for longer than 2 months for support (the same percentage as reported by Healthwatch Richmond) however, 51% (20 out of 39 people that answered this question) had not been diagnosed, highlighting the potential for substantial unmet need. Some people also reported that they had chosen to pay privately for access to specialist care as the waiting list was too long.



My GP was understanding and did blood tests and a chest X-ray but was not able to refer me to a Long Covid clinic, only to respiratory at Kingston Hospital which was about a 6 month wait time. I privately paid for a respiratory physician who had experience with Long Covid at the Royal Brompton, who then transferred me to their NHS services where I did further tests. I then saw a private cardiologist at the Royal Brompton...I also paid privately for respiratory physio. I've now had the call from respiratory at Kingston Hospital to say they will keep me under their Covid clinic and will call me back in 3 months as I am improving slowly on my own which is fine. GP also referred me to a new community Covid clinic where I am seeing and NHS respiratory physio which is good. That physio is also referring me to her occupational therapist colleague with help on pacing for chronic fatigue."

Pre-existing conditions play a role in determining both the appropriate care and support required, as well as confusing and complicating the situation for patients. Lack of a formal Long Covid diagnosis appears to be deterring some GPs from referring to relevant services.

Although respondents acknowledged that GPs (in the main) were responsive to their patients’ concerns, some felt dismissed, and one was told to just “wait and see” which caused anxiety.

“I had a couple of phone consultations with my GP. One about my diabetes and another about a referral for arthritis. When I mentioned the ongoing Covid things she explained that I should wait and see because no one really has answers yet. I know I shouldn't have asked about more than one thing during the consultation to be fair.”

“I contacted my GP very early on and they finally referred me to a chronic fatigue clinic at my request after a lot of badgering a few months later. Initially they advised me I probably had post viral fatigue and not to do too much but it was hard to know exactly what that meant in practice. I was assessed by the chronic fatigue about 3 months later and was given better advice about what pacing meant and how to gradually get better.”

Waiting times for referrals were of concern to many respondents, and once tests were completed, there appeared to be a breakdown in communication for some. Healthwatch Kingston learned of test results being delayed and issues raised about the lack of follow up with patients. Waits for mental health support were also described as too long, but once people found themselves in the system the help these provided was found to be helpful.

The need for support with managing day to day responsibilities both at home and work was a recurring theme with respondents. Those with pre-existing conditions were often confused over their symptoms, some feeling that they are not being treated at all for the Long Covid symptoms in the same way as those with new symptoms (e.g., Menopause or chronic fatigue syndrome).

The following response illustrates the complexity that one person had been navigating while seeking an accurate diagnosis:

> “*I have been in touch with my GP, and they have referred me for heart scans and ECGs. I went to A&E at St Helier Hospital a few times in the first few months and got two chest x-rays done there. I also have blood tests every few months when I go back to the GP as and when my symptoms have worsened/changed. I have been diagnosed with Hashimoto’s disease, which could be contributing significantly to my symptoms. But my thyroid levels have been largely normal, so the doctors think there is something else going on i.e., Long Covid. Since my relapse, I have been referred for more blood tests and my thyroid levels were slightly out, so I have changed medication levels and must go for another blood test. If my levels are normal, the GP says they will refer me to the Long Covid clinic. But they don't know much about it, and they have warned me the waiting list will be long. The GPs have been lovely and have supported me as much as they can. But they always tell me that Long Covid is new and they're not sure what they can do for me. So, I do feel like I've had to largely manage my symptoms and their impact on my own at home. I haven't seen a GP in person.”*

The different needs for support appear to be as varied as the symptoms described, and the ability for both patients and clinicians to differentiate between clinical support needs and the ongoing challenges with mental health remain a major challenge.

7. What you said would make a difference

At the outset of this community engagement, Healthwatch Kingston was keen to understand what would make a difference to local people. This is what some Kingston survey respondents said would help:

"Advice on lifestyle, supplements, diet that might help? Knowing what help is available and what research is being done."

"To be diagnosed."

"It would be great to get some support on helping with brain fog as I find this the most debilitating symptom."

"I'd like some 121 support from a trained medical professional. Even if I can't get a diagnosis or a cause for my symptoms, I would like some support in pacing and in nutrition, as these seem to be the things that have made most improvement in others and in my own symptom management. It is hard to know what to do for the best and it has all been guesswork on my part. It is difficult to maintain and find motivation as a result. I'd also like support in transitioning from the person I was before to the person I am now. For example, help in finding a new job and suggestions on what I might be able to manage. And suggestions for how to adapt my home and fit my energy levels around necessary tasks like housework. Citizens Advice Kingston were helpful in explaining benefits I might be entitled to, but I want to know how I can thrive with this condition, not just survive on the bare minimum. I want to get better ideally. But living with bipolar II has taught me that with the right lifestyle changes and management strategies, I might be able to have a much better quality of life than I do now. Sadly, I am so fatigued that I can't work out such big changes for myself. I need help."

"An exercise group may be helpful to get lungs back working well/help ameliorate tiredness maybe or physiotherapy to help with chest pain, unsure really."

"I need support with daily activities due to my conditions. I need help collecting the kids, cooking meals or pushing a wheelchair and there isn't a referral for this kind of help."

A few more things you said would help you manage better:

"Trauma support may have been useful. I was blue lighted to hospital in the beginning of Covid-19. They wouldn't test you unless they admitted you and it was such a shambles at A&E, I wanted to go home. Did my own peer reviewed research on SARS/MERS, bought my own oxygen, 4 times a day and took aspirin against official medical advice at the time as I was worried about clots due to my reading. No follow up. Off work for 2 months. Info scant due to uniqueness of virus. Positive for antibodies June 2020 via work. Struggled with work tasks, pandemic still misunderstood. Lack of understanding as new virus. One size does not fit all and more support or some follow up even though on the day of your tests the results were good, the symptoms fluctuate."

"Help at work some days as the fatigue is so bad, I have to drag myself to work which does not help. Surely, they must know it's in their interest I get better. I was told to go get another job if i was not happy."

"Physical rehab support to safely help become active after months at home being sedentary.

"People keep referring to waiting times once you're referred to a service as being 2 month or 5 month etc., however, they appear to be forgetting the 3 months you have already been suffering."

"I need better social work support; my life has been turned upside down by this. Where is the joined-up thinking?

"How to retrain your taste and smell."

8. In conclusion

This survey has illustrated that the impact of Long Covid on our Kingston residents is challenging, debilitating and life changing for many, and also for the NHS, Kingston Council, voluntary and community organisations who are attempting to manage the needs of service users.

Service user views must remain integral to the process ahead in determining types and levels of provision for Kingston residents living with Long Covid, and in furthering any future projects aims and outcomes.

Given the detailed responses to this community engagement shared by people affected by Long Covid, and the medical and support service required to help people manage, multi-disciplinary teams and planning forums are necessary. More work is required to disentangle the complexity of Long Covid symptoms, the changes people experience and support needs as they recover.

GPs need to be well placed to engage with other providers in innovative ways such as collaborating with other specialist colleagues to deliver services in a range of settings. These innovations will require good local relationships, adequate resources, and access to specialist training.

Pressure on the NHS, with long waits for services across the healthcare system, will remain a serious challenge for the foreseeable future, and is unlikely to improve in the short term.

Financial constraints coupled with a diminished workforce and overwhelming demand will lead to continuing struggles for patients, other service users, healthcare professionals and commissioners alike, and aiming to provide an appropriate level of care to meet the complexity of Long Covid will require services to develop considerable “know how” to navigate around the complexities, inflexibilities and the limitations of all the different funding streams and contracts. There is opportunity to support the required collaborative approach as the SW London Integrated Care System is established and transferrable lessons to be learned from Long Covid care management which may well benefit other approaches to care for longterm medical conditions.

Workforce issues may further challenge the process of developing appropriate and timely levels of provision, and confident commissioning will be required.

Active participation from service users and a solution focused outlook from all key partners and stakeholders will be required, putting the complex needs of patients and service users at the very heart of any service development. Without this cooperation and collaboration, it will be difficult to find a common enduring agreement and shared ownership of the challenges ahead, merely reluctant participation and limited support for the process.

Healthwatch Kingston welcomes the inclusive work being done by the Kingston and Richmond Post-Covid Steering Group in co-producing the aims for the Kingston and Richmond Long Covid service. Understanding the softer indicators, (such as the rich qualitative data within our ‘Living with Long Covid’ report) and listening carefully to the real and lived experience of those impacted by Long Covid will lead to the development of short, medium, and long-term service plans for the provision of care to people living with Long Covid.

9. Thank you and next steps!

Healthwatch Kingston would like to thank everyone that has contributed to the production of this report, particularly our volunteers and other local people that have shared their experiences of living with Long Covid with us. Everything we say and do is informed by what local people tell us.

All Healthwatch Kingston reports are published on our website. This report will be shared with the Kingston and Richmond, and also the SW London Post-Covid Steering Groups (we will produce a common themes report with other Healthwatch work in SW London), Healthwatch England, the Care Quality Commission, the Royal Borough of Kingston upon Thames, south west London Clinical Commissioning Group, Voluntary and Community sector and other stakeholders, such as:

Kingston University and Kingston and Cardiff University researchers leading the 'LISTEN' project who have agreed to use our findings to inform their work.

LISTEN is a 2-year project recently funded by the National Institute of Health Research (NIHR) and aims to work in partnership with individuals living with Long Covid to design and evaluate a package of self-management support personalised to their needs. If you are interested in any aspects of the LISTEN project, such as the advisory group, codesign groups, or the trial (that is starting spring 2022), please contact the LISTEN email and register your interest listen@cardiff.ac.uk

Healthwatch Kingston will also continue our work with the Kingston and Richmond Post-Covid Steering Group and contribute to the work of the Post-Covid-19 Proactive Case Finding Task and Finish Group with NHS England and NHS Improvement.

> ***“We would like to congratulate Healthwatch Kingston on a comprehensive and professional report looking at the impact of Long Covid on Kingston residents. The report provides data and insights which the Kingston and Richmond Post-Covid Steering Group will be able to use to inform the Aims of the Steering Group and the further development of local Long Covid Services. We look forward to continuing to work closely with Healthwatch Kingston in this area.”***

Dr. Annette Pautz and Denise Madden,

on behalf of the Kingston and Richmond Post-Covid Steering Group

Appendices

Appendix A: Further resources used by Healthwatch Kingston while scoping and producing this report

- NHS Your Covid Recovery Your Covid Recovery | Supporting your recovery after Covid-19

- Facebook. Long Covid Support Group. Long Covid Support Group | Facebook

- Asthma UK and British Lung Foundation. Post-Covid hub. Post-Covid HUB - By Asthma UK and British Lung Foundation (post-covid.org.uk)

- Royal College of Occupational Therapists. How to conserve your energy: Practical advice for people during and after having Covid-19. How to conserve your energy – RCOT

- National Institute for Health and Care Excellence (NICE), Scottish Intercollegiate Guidelines Network (SIGN) and Royal College of General Practitioners (RCGP) Covid-19 rapid guideline: managing the longterm effects of Covid-19 (published on 01.02.2022).

Appendix B: If you have been diagnosed with Long Covid, or waiting to be diagnosed, please tell us more about your experience?

I have been diagnosed with Long Covid	*“I tested positive for Covid on 26 December 2020 and was bed ridden for 3 weeks but took another 6 months to get to the point where I was able to return to work part time. I was diagnosed by my GP with Long Covid and was referred to the Epsom and St Helier Hospitals Chronic Fatigue Clinic.”*
	“Periodic shortness of breath, memory problems fatigue thigh muscle pain. Had Covid March 2020, sick for approximately 3.5 weeks then. Just wiped out. Symptoms improved after second vaccine May 2021 although still having some symptoms.”
	“I was diagnosed with Long Covid based on symptoms, as I couldn't get a test when I first got sick in April 2020. I was given the diagnosis in June 2020.”
	“I have had continuous overwhelming fatigue, breathlessness, brain fog, change in taste and smell, trouble sleeping. My GP and various consultants have all said that I have Long Covid. I know I have Long Covid. It has affected my lungs, heart, brain, gut, kidneys as far as I know.”
	“Chest x-rays and blood tests revealed nothing abnormal. Telephone assessment by Long Covid clinic at Kingston Hospital. Referred to online Active Breathing Course. Symptoms are relatively mild, day to day is fine but unable to exercise above certain intensity as become breathless / tight chested. Improving slowly, month by month.”
	“I had severe problems with asthma during and following Covid requiring 8 weeks of oral steroids, changes and increases in asthma medication. Since Covid in January, I have been experiencing migraines every few days - having never had them before. They have been very debilitating and necessitated a lot of time off work due to the exhaustion, pain, and nausea. Interestingly, a consultant prescribed magnesium and Vitamin B daily supplements and since taking them I have not had a migraine. I have an underlying gastro condition and since Covid have been in a bad flare up requiring weekly day unit visits at Kingston Hospital. My mental health has been a real struggle.”

I have been diagnosed with Long Covid	*“I caught Covid in March 2020. At the time, getting a test was near impossible but my husband bought 2 for us. I was day 12 of symptoms and mine came back negative but my husband was on day 5 and his was positive. Since then, I have suffered with extreme fatigue, brain fog, change to my taste and I kept getting infections (tooth with removal, sinus, fingers). It was until January 2021 when I was being prescribed course number 10 of antibiotics that my GP said it could be Long Covid and sent me for blood tests. I was then told I'd be referred to a Long Covid Clinic and got a chest scan and ECG in March 2021 but since then have not heard anything else (they did say the wait would be long, but I had not expected this length of time. I have been part of a Long Covid rehab programme with Nuffield health which has been great.”*
	“I got Covid in Spring 2020. I thought I was better and then experienced really bad respiratory issues. Waking up in the night gasping for air and having to take an inhaler, not being able to sleep without vapour rub on my chest and having to sleep sitting up. I would get tired from the shortest walk and had to sleep lots but found sleeping really hard due to not being able to sleep lying down. Doctors did lots of tests and could see my lungs were very inflamed. At first I was told it was anxiety but then they linked it to Covid.”
	“I was diagnosed during a telephone consultation. Told I could be on a waiting list for over 6 months, so I said I'd hopefully get better by then and not to bother putting me on the list.”
	“GP and Respiratory Physician confirmed Long Covid.”
	“Persistent breathlessness and fatigue. Increased asthma symptoms. Have had to go to the doctors for 16 appointments since I had Covid in January 2021, I asked my GP to refer me for Long Covid support once it was 12 weeks post Covid as clearly my symptoms were persisting.”
	“I had to wait over a year to get an appointment in a Long Covid management clinic which was a waste of time as everyone else had Covid in the second wave. One doctor said to me when I was sent to hospital because they thought I had blood clots on my lungs it’s a mystery to me as to what you are doing here and what makes you think you have had Covid.”

Have symptoms but not yet been diagnosed	*“After suffering with Covid in the summer and many of my symptoms not improving I called the GP. After a 30min wait to talk to the receptionist all appointments were taken. When I explained my symptoms and told them I thought I may have Long Covid they found me an appointment later that afternoon. The Doctor was very helpful and immediately referred me to the hospital for further investigation. Blood tests, chest x-rays and are going to investigate my palpitations.”*
	“I had Covid in April 2020 and lost my sense of taste and smell on Day 3. I still do not have full taste and smell.”
	“My 13-year-old daughter prior to catching Covid has been fit and healthy, but now she’s constantly feeling unwell, the GP has just told her to take vitamins and has dismissed any potential of Long Covid.”
	“My young niece works as a fitness instructor and since having Covid is now constantly fatigued and the GP requested a blood test, which led to her being put on vitamin supplements.”
Other	*“Awaiting diagnosis from GP, awaiting blood and x-ray results and follow up with GP. I am experiencing chest pain, shortness of breath and extreme tiredness. I experienced brain fog for 3-4 months after testing positive and felt like I had forgotten things I once knew how to do, especially at work, however this has improved a bit. I struggle to get to sleep with chest pain. I am exhausted and found myself sleeping a lot and falling asleep during the daytime which is unusual for me (pre-Covid).”*
	“I have been suffering with Long Covid since March 2020. Have never been officially diagnosed with LC but have been treated under the banner of ‘suspected’ Covid. Testing was not available in March 2020 in the local community.”
	“2 months or more tired and lethargic, heart pain, breathing oxygen issue, muscles aching, brain fog.”
	“With no treatments being available from the outset, experiencing the tidal wave of frightening and unexplainable symptoms, alongside not being able to breathe properly, or function normally, and having relentless chest pains was traumatising. With blood tests that kept coming back normal, PCR tests not being available in the community and by the time antibody tests became available I was already 4 months into Long Covid so received a negative result. All of this made validation impossible, and discrimination became an issue because the early Long Covid clinics required proof of a positive PCR test.”

Appendix C: Healthwatch Kingston Living with Long Covid survey

About our survey:

Long Covid is defined as signs and symptoms that continue for more than 12 weeks and develop following an infection consistent with Covid-19. You may experience Long Covid even if you were not acutely ill in the first place. Common symptoms include breathlessness, brain fog and fatigue. Not everyone with Long Covid, particularly those who were ill early in the pandemic, will have been tested for Covid-19.

If you have been experiencing the symptoms of Long Covid (also known as Post-Covid Syndrome), whether or not you tested positive for Covid-19, then please share your experience by completing the survey.

Your feedback will help us to understand what support is needed for people living with Long Covid and will be used to produce a report to inform the relevant organisations of what you have been experiencing, and recommend how they can design services and support to better meet your needs.

We will provide an independent, anonymised report of our findings to service providers and commissioners of NHS and social care.

If you have any questions about this survey or wish to give us more information about your situation, please contact us at info@healthwatch-kingston.org.uk or by phone: 020 33261255, please leave a message with your contact email/phone number, and one of our team will get back to you.

Healthwatch Kingston is the local champion for health and social care services working with, but independently of, the NHS and Kingston Council.

Thank you for taking part in this survey.

Personal Experience

**** 1.** Which borough do you live in?*

☐ Kingston
☐ Croydon
☐ Merton
☐ Richmond
☐ Sutton
☐ Wandsworth
☐ Other (please specify)

***2.** Who is completing this survey?*

☐ I am completing this survey for myself
☐ I am completing this survey on behalf of someone else (please answer the remaining questions on behalf of the person)
☐ Other (please specify)

3.** Did you have a disability or long-term health condition before the Covid-19 pandemic? **(We are asking this question to understand if this may have impacted on the Long Covid support that you received, or otherwise).

☐ Yes - physical or mobility impairment
☐ Yes - Sensory impairment
☐ Yes - Learning disability or difficulties
☐ Yes - Mental health condition
☐ Yes - Long term condition
☐ No

☐ Prefer not to say

☐ Unsure

☐ Other (please specify)

4. *Not everyone who has Long Covid will have been diagnosed with either Covid-19 or Long Covid.* ***We still want to hear from you either way. We want to know what it's like getting diagnosed and whether having a diagnosis makes a difference to your experience. Which of the following best describes you?***

☐ I have been diagnosed with Long Covid

☐ I am experiencing/have previously experienced Long Covid symptoms but not yet been diagnosed

☐ Other

If you have been diagnosed with Long Covid, or waiting to be diagnosed, please tell us more about your experience.

5. *Before being diagnosed with Long Covid or experiencing symptoms, did you receive a positive Covid-19 test result?*

☐ Yes

☐ No

If yes, please can you tell us how your positive result was confirmed? (E.g. by a GP, at hospital, home test kit etc.).

6. *For how long have you been experiencing/did you experience Long Covid symptoms?*

☐ 1 month

☐ 3 months

☐ 6 months

☐ 9 months

☐ 12 months

☐ Over a year

7. What are the main symptoms you have experienced or are still experiencing?

8. How have your symptoms changed since you started experiencing them?

9. Has living with Long Covid had an effect on your life?

Tell us what it has been like and how it has affected you, your quality of life, relationships, wellbeing, your ability to work, complete caring and parental roles and anything else.

10. Has living with Long Covid impacted your Mental Health? If yes, please tell us more about the effects this has had on your life?

Support Accessed

11. Have you been in touch with your GP or a hospital about your support needs? If yes, which one, and what support have they provided/referred you to?

12. What type of other community support have you received and was it satisfactory?

13. If you have been diagnosed with Long Covid, how long have you had to wait before receiving support, after your first referral?

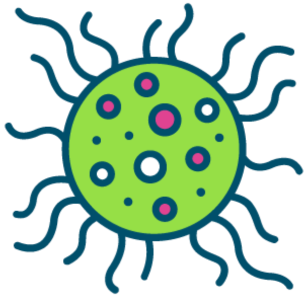
☐ Less than 2 weeks
☐ Between 2 weeks and 1 month
☐ Between 1 month and 2 months
☐ More than 2 months
☐ Unsure
☐ I have not been diagnosed with Long Covid

14. *If you have accessed support, please tell us if and how this has made a difference to your health?*

15. *Do you have anything more to tell us about any support you have accessed?*

16. *Is there any other support that you're not currently getting that you think would help you? Tell us what support you think would help.*

17. *Is there anything else you would like to share with us or that we should have asked you?*



Tell us what you think about NHS and social care.

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