healthwatch
Havering

Community Engagement

Post-COVID Syndrome (Long COVID): The continuing effects in Havering

Focus Group discussions

Volume 1: Report

May 2024

What is Healthwatch Havering?

Healthwatch Havering is the local consumer champion for both health and social care in the London Borough of Havering. Our aim is to give local citizens and communities a stronger voice to influence and challenge how health and social care services are provided for all individuals locally.

We are an independent organisation, established by the Health and Social Care Act 2012, and employ our own staff and involve lay people/volunteers so that we can become the influential and effective voice of the public./

Healthwatch Havering is a Community Interest Company Limited by Guarantee, managed by three part-time directors, including the Chairman and the Company Secretary, supported by two part-time staff, and by volunteers, both from professional health and social care backgrounds and lay people who have an interest in health or social care issues.

Why is this important to you and your family and friends?

Healthwatch England is the national organisation which enables the collective views of the people who use NHS and social services to influence national policy, advice and guidance.

Healthwatch Havering is your voice, enabling you on behalf of yourself, your family and your friends to ensure views and concerns about the local health and social services are understood.

Your contribution is vital in helping to build a picture of where services are doing well and where they need to be improved. This will help and support the Clinical Commissioning Groups, NHS Services and contractors, and the Local Authority to make sure their services really are designed to meet citizens' needs.

'You make a living by what you get,

but you make a life by what you give.'

Winston Churchill

Community engagement

Under Section 221 of the Local Government and Public Involvement in Health Act 2007, Healthwatch Havering has a statutory duty to ascertain the views of health and social care services and to make them known to the commissioners and providers of those services so that they can be taken into account in the development, commissioning and delivery of services.

We do this in a variety of ways, such as surveys, interviews and focus groups.

We also participate, with other Healthwatch organisations across North East London, in the Community Insights System, which gathers views and comments on health and social care from people across the area. Intelligence gained from Community Insights is used directly in, or to inform, many of the surveys and other public engagement events that we carry out.

The results of our community engagement are shared with Havering Council, NHS North East London, NHS and other provider organisations and Healthwatch England.

"I think part of the problem is that COVID didn't exist as a thing until the end of 2019. Doctors have been trained to take some symptoms and say "You've got that"; and if they can't do that, they're really in bother because the doctor's job is to give you a medication or whatever and then you're going to get better. … With Long COVID, they can't do that, so they find themselves, I believe, in a very difficult situation. But the bit that I really worry about is the fact that it is so difficult to get to the Long COVID team." - Participant E, Session 1

Contents

For online versions of this report, this Contents list is interactive: click the entry below to go to the section you wish to read.

	Page
Executive Summary	**4**
Introduction	**5**
Long COVID	**6**
Long COVID in Havering	**7**
Origins of this report	**9**
Methodology: Focus Group discussions	**10**
The impact of Long COVID on day-to-day living	**11**
A. Fatigue, brain fog and feeling frustrated	**12**
B. Sleeplessness and insomnia	**14**
C. Headache, memory and forgetfulness	**15**
D. Effect on working life	**17**

The impact of Long COVID on day-to-day living (continued) **Page**

E. Other senses and mobility 18
F. Daily activity 19
Accessing healthcare services 21
A. Primary care services 21
B. Talking Therapy 25
C. Other therapies 26
D. The NELFT Long COVID clinic 28
E. The system 29
F. Vaccination 31
Support needed 33
Peer support needs 35
Conclusions 37
Suggestions for action 39
1 Prompt Medical Care 39
2 Understanding and Recognition 40
3 Comprehensive Support Services 40
4 Advocacy and Validation 41
5 Inclusive Treatment 42
6 Mental Health Support 42
7 Peer Support Groups 43
8 Streamlined Referral Processes 43
9 Tailored Care 43
Acknowledgements 45

Executive Summary

This report builds on earlier reports we have published and work previously carried out by the Healthwatch organisations in Barking & Dagenham, Havering and Redbridge, which examine the effects of Long COVID on people in Havering.

For this report, we invited people who had responded to our earlier surveys about the effects of Long COVID, together with some patients who had been seen at the Long COVID Clinic at King George Hospital, provided by NELFT., to attend a series of Focus Group sessions at the end of May 2024. Four sessions were held, two in person at Hornchurch and Harold Wood Libraries respectively, and two by video conference. 21 people with experiences of Long COVID ranging from little more than inconvenience to near-total incapacity took part in these events.

Unsurprisingly, what they told us did not greatly differ from what we had found out in the previous surveys but the participants were able to tell us about their experiences in much greater detail.

The report comes in two volumes – this volume summarises what the participants in the focus groups told us; Volume 2 is a full transcript of all four focus group sessions.

Selected direct quotations from participants are included within the narrative, in darker green font, with links to Volume 2, the full transcripts, to see the full context of the quotations.

Introduction

The Coronavirus (COVID-19) pandemic emerged onto an unsuspecting world in early 2020, when reports of a high level of infection by a previously unknown virus circulating in the Chinese city of Wuhan first came to attention. By late March, infection in the UK had reached a sufficiently high level to call for unprecedented action by the government effectively to close society by imposing the first of several periods of lockdown: "stay home, stay safe and protect the NHS" [1].

There was, inevitably, an initial period of confusion until things settled down into what would prove to be a then unforeseen period of disruptive pandemic – even now, more than four years later(Summer 2024), the effects of the pandemic remain, and the regular offer of COVID vaccinations to the clinically vulnerable remains.

Inevitably, the first focus was on dealing with the unforeseen (and unprepared for) pandemic and the fatalities that it led to. No human immune system had previously come across the coronavirus responsible for COVID-19 and there was thus little, if any, natural immunity to an infection, so that those regularly in contact with the viral infection or who had compromised immune systems were particularly susceptible to its fatal effects. Although the rapid development and deployment of several vaccinations made a significant difference, it gradually

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[1] Prime Minister Boris Johnson, addressing the nation on 23 March 2020.

emerged that, whilst most people who survived infections were able to recover fully, a significant minority continued to suffer symptoms of infection, some very severely, although no longer actively infected by the virus. The Focus Group sessions now reported on took place more than four years after the first appearance of the virus, yet among those telling us about their experience of Long COVID were people who had become infected by it from the very earliest days who were continuing to experience its after-effects, as well as those infected much more recently.

Long COVID

The NICE guideline (initially published in December 2020, updated in November 2021) covering the management of the long-term effects of COVID-19 has included the following clinical definitions within its definition of 'Long COVID' (National Institute for Health and Care Excellence, 2021):

- ***Ongoing symptomatic COVID-19****. signs and symptoms of COVID-19 from 4 to 12 weeks*
- ***Post-COVID-19 syndrome****. signs and symptoms that develop during or after an infection consistent with COVID-19, continue for more than 12 weeks and are not explained by an alternative diagnosis.*

Long COVID not only has an impact on the individual but is suspected to introduce an added burden to the wider population including the NHS.

Return to Contents page

Long COVID in Havering

In August 2022, Havering Council published a Health Needs Assessment (HNA) of Long COVID [2] to understand the local needs associated with Long COVID. Within the HNA, an estimate from the UK Health Security Agency (UKHSA) for Long COVID cases was provided. UKHSA estimated that, as of March 2022, 7,230 residents in Havering were expected to have Long COVID and 1,265 residents would need NHS support.

The effects of Long COVID vary widely from person to person. For some, it is merely an inconvenience: a persistent cough perhaps or some loss of taste (e.g. coffee or tomato ketchup tasting bitter); for others, the long-term effects of symptoms are still debilitating and distressing.

While the number of COVID-19 cases has reduced as the world has emerged from the pandemic, testing data collected by the UK Health Security Agency (UKHSA) suggests that people are still being infected by COVID-19. The latest rate was 3.05 per 100,000 population in Havering on 3 July 2024(see Figure 1 overleaf).

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[2] See **London Borough of Havering: Long COVID Health Needs Assessment**

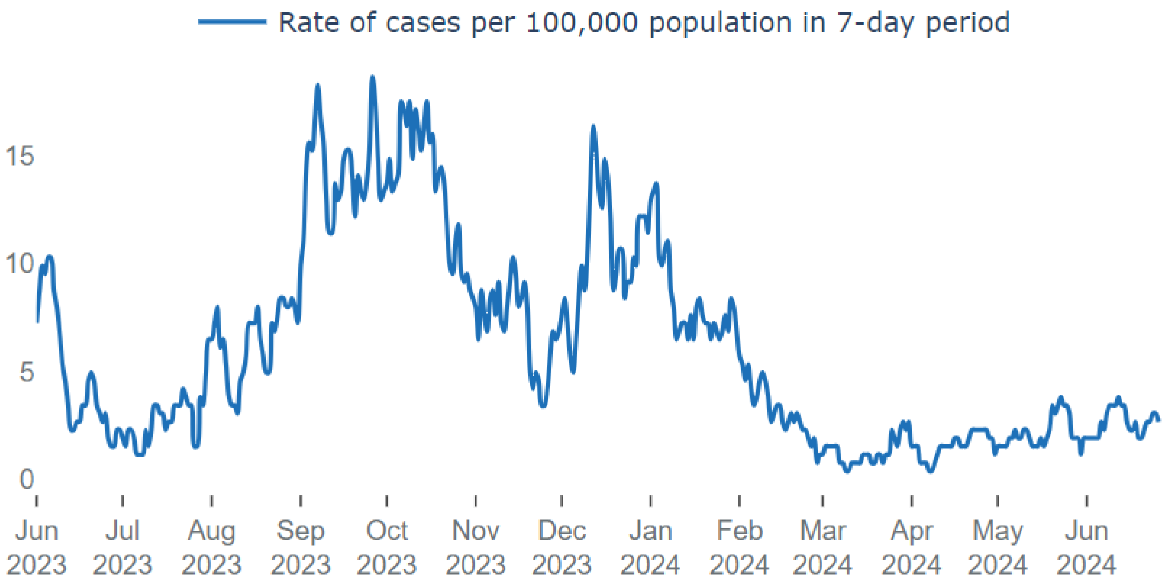

Figure 1: Rate of cases per 100,000 people in the rolling 7-day period in Havering, 1 July 2023 to 3 July 2024

The changes in the national testing policy whereby testing is no longer a standard requirement may affect the number of positive cases reported. It is likely that the rate reported by UKHSA is an underestimate of the number of COVID-19 infections in Havering.

However, successful rollouts of the COVID-19 vaccination programme have probably contributed to a reduction in the number of COVID-19 cases nationally[3]. In addition, research has shown that the COVID-19 vaccines c.an reduce the risk of Long COVID symptoms[4].

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[3] See **What do we know about covid vaccines and preventing transmission? [*BMJ* 2022;376:o298]**

[4] See **The effectiveness of COVID-19 vaccines to prevent long COVID symptoms [Lancet Respir Med 2024: 12: 225-36]**

Return to Contents page

Nevertheless, some of those who previously had an acute COVID-19 infection developed Long COVID. There is still a risk that individuals who have acute COVID-19 infections could go on to develop Long COVID. In March 2024, the Office for National Statistics estimated that approximately 3.3% (2 million) of people living in private households in England and Scotland were experiencing self-reported long COVID[5].

Origins of this report

In 2021/22, the three Healthwatch organisations in Redbridge, Havering and Barking & Dagenham, in collaboration with the NELFT Long Covid Clinic at King George Hospital, and NHS North East London conducted a survey [6] to help shape and develop services in this, then new, clinical area. This was followed in by a survey in 2023 [7] in conjunction with Havering Council's Public Health Service and the Havering North Primary Care Network, who wanted to build on the findings of the 2022 tri-borough survey by finding out the current situation in Havering.

Subsequently, we were asked to conduct some Focus Group sessions to understand the effects of Long COVID in greater depth. It is those Focus Groups that are now described in this report.

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[5] See **Self-reported coronavirus (COVID-19) infections and associated symptoms, England and Scotland [ONS 25 April 2024]**

[6] See **The Experience of Post-Covid-19 [Healthwatch Barking & Dagenham, Havering and Redbridge, 2022]**

[7] See **Post-COVID Syndrome (Long COVID): The continuing effects in Havering [Healthwatch Havering, October 2023]**

Return to Contents page

Methodology: Focus Group discussions

The discussion at each Focus Group session followed broadly the same pattern, although each session had a different dynamic, depending on how participants responded. All comments mentioned in this report are anonymous and, as far as possible, all identifying personal data has been removed. The topics covered in the sessions were:

1. What symptoms have had the most significant impact on your ability to do day-to-day activities and your quality of life?
2. Can you tell us about your experience with accessing services to help you with your symptoms (this includes local services):
    - How did you find out about these services?
    - What has worked well for you?
    - What has not worked well for you?
3. What further support or services would help you manage your symptoms?
4. Do you think a peer support group would be beneficial? If yes, why do you think so? If no, why do you think it would not be beneficial?

Return to Contents page

The impact of Long COVID on day-to-day living

Participants outlined the experiences and challenges they faced in dealing with health issues. They mentioned struggles with chronic fatigue, pain, insomnia, and the lack of effective treatment options provided by healthcare professionals. They expressed frustration with the limited support they had received and the impact of their condition on daily life.

The challenges participants faced with Long COVID, as explicitly mentioned by them, included:

- **Unpredictable fatigue that varied from day to day, making it difficult to conduct daily activities.**
- **Loss of smell and taste, with altered or diminished senses affecting their enjoyment of food and scents.**
- **Breathing difficulties, including the need to consciously think about breathing and experiencing moments of forgetting to breathe.**
- **Brain fog, leading to memory issues, difficulty concentrating, and challenges with communication and writing.**
- **Mobility issues, such as the inability to lift arms, climb stairs, or perform physical tasks without assistance.**

- **Weight changes, with some participants experiencing weight gain due to prolonged bed rest and fatigue.**
- **Impact on work, including reduced ability to concentrate, type, and work as they did before.**
- **Accessing healthcare services, such as delays in seeing specialists like neurologists and physiotherapists.**
- **Emotional impact, with participants expressing frustration, disappointment, and a sense of loss over their changed abilities and lifestyles due to Long COVID.**

A. Fatigue, brain fog and feeling frustrated

The term "brain fog" is clearly not used in medical diagnosis, but it was so widely used by participants in both these focus groups and in previous surveys we have carried out and is so widely referred to despite everyone's perception of it differing, that using it in this report was unavoidable.

Participants described experiencing symptoms such as fatigue, brain fog, muscle aches, memory issues, disrupted sleep patterns, and difficulties with concentration and physical tasks. Long COVID had affected their ability to work, with challenges in keeping focus, memory, and energy levels. Some had had to reduce their working hours or adapt their work environment to

Return to Contents page

accommodate their symptoms. They felt frustration with the impact of Long COVID on their daily lives, social interactions, and mental well-being and highlighted the difficulty of explaining their condition to others and the profound changes it has brought to their routines and activities. They faced challenges in effectively communicating their symptoms and needs to healthcare providers and spoke of being misunderstood or dismissed in medical settings.

> *"Long COVID has left me same as [Participant N] with brain fog, forgetting words, headaches that I can't shift." –* Participant O, Session 3
>
> *"… you just forget everything and get incredible fatigue … although I'm almost through the symptoms now, I found that my brain fog got so much acute. I would literally be watching TV, and if an ad came on or I turned away, I couldn't remember what I was watching." –* Participant P, Session 3
>
> *"… I have brain fog, really bad, like forgetting the words and forgetting what you're talking about and all those things. I put on loads of weight because I literally was in my bed for like 3 years. Literally just fatigue so bad, but then couldn't sleep but just felt so tired all the time." –* Participant R, Session 3

Participants shared strategies they had adopted to cope with Long COVID, such as managing energy levels, setting reminders, engaging in cognitive exercises, and adjusting daily routines to conserve energy and improve productivity.

Return to Contents page

The long-lasting impact of Long COVID on various aspects of life, including work, social interactions, and personal hobbies, was a common theme among the participants, highlighting the need for ongoing support and understanding.

> *"Unfortunately, I have had three bouts of COVID since then and now I'm down to part time with a long line of sickness behind me because long COVID has left me with brain fog, forgetting words, headaches that I can't shift"* – Participant O, Session 3
>
> *"I think for me, the biggest symptoms are really the brain fog. I didn't even know there was such thing as brain fog. I just thought I was getting super old, I thought* "Is this what getting old is all about?" *And you just forget everything and get incredible fatigue"* - Participant P, Session 3

B. Sleeplessness and insomnia

Insomnia was a persistent issue in post-Long COVID recovery. The physical and emotional toll of their health conditions, emphasising the need for more comprehensive and tailored medical interventions to improve their quality of life.

One participant described feeling like they are just surviving each day, not truly living, feeling permanently tired, with some days being worse than others, comparing their energy levels to starting the day using a mobile phone with only 30% of battery life left. The participant added that they experienced a combination of exhaustion and pain daily, with the pain level typically around 7 or 8 on a scale of 1 to 10, but sometimes

Return to Contents page

reaching 10, 11, or 12; their pain was unbearable, especially from their shoulders and neck up, and from their hips down to their little toe every day.

> *"No day is a good day, but it's literally like I'm dragging myself around, to do anything is an effort. It's all from my shoulders and neck and up, here is the worst that that can come and go but from my hips down to my little toe every day. I'm 38 and I feel like I'm 100 and the pain is unbearable, It's literally unbearable."* – Participant L, Session 2

Another participant expressed frustration at not being able to do many things for themselves and that their family was having to function as part-time carers due to their limitations. Their struggles with sleep meant that they could fall asleep quickly due to exhaustion but constantly wake up throughout the night.

> *"I forgot to mention about insomnia. I've found one of the ongoing things since getting Long COVID is insomnia. Saturday night I slept for quite a few hours and it's like '* Wow, that's a miracle'" – Participant E, Session 1

C. Headache, memory and forgetfulness

Participants had experienced various symptoms and challenges after contracting Covid-19 including severe headaches, forgetfulness, difficulty managing daily tasks, reliance on notes, and a decline in physical abilities. They also mentioned the

Return to Contents page

impact of shielding due to asthma and the change in their social life post-infection. They described facing fatigue, muscle weakness, neck pain, altered sense of taste and smell, sleep disturbances, short-term memory issues, and difficulty recalling words. The lingering effects of Covid-19 on their physical and cognitive functions were affecting their daily lives significantly.

For one participant, forgetting a doctor's appointment had a significant impact. They mentioned that they saw the appointment on their fridge calendar early in the morning but then forgot about it shortly after. By the time they remembered, it was too late, and they had missed the appointment.

Another participant had experienced several memory challenges:

1. Short-term memory issues: struggling with remembering things in the short term, especially when interrupted. They found it difficult to recall what they were doing or saying after a brief interruption, even for a matter of minutes.
2. Word recall difficulties: they had trouble remembering words and spelling them correctly. They can visualise the word in their mind but struggle to articulate it or write it down accurately.

Return to Contents page

3. Long-term memory unaffected: While short-term memory was affected, long-term memory, such as childhood memories, had remained intact.

> *"My long-term memory is great, I can remember what I did as a kid and stuff like that, my long-term memory is not affected. It's just my very short-term memory and when I say "short-term" I do mean like for a matter of minutes and not hours or days. It's just those few minutes in between somebody interrupting me when I'm doing something and me continuing to do it"* – Participant S, Session 4

D. Effect on working life

Participant N (at Session 3) told us how their working hours had changed over time:

- Initially, they had worked 35 hours a week as a stay-at-home typist
- After contracting COVID, their work hours decreased to 20 hours a week
- Subsequently, their work hours further reduced to 15 hours a week
- The hours decreased again to 10 hours a week
- Eventually, the individual found themselves unable to concentrate as before, leading to a further reduction to working only 3 hours a day for two days a week.

Return to Contents page

- Currently, the individual has not worked since October 2023 due to the challenges they face with concentration and typing, indicating a significant decrease in their work hours over time.

Other participants had had similar experiences, for example:

> *"I used to run an office of like 40 people and I had all these people working for me. Now I can't even manage my house. I have a cleaner, I have a gardener, I have someone who does the ironing. I'm very lucky I get that"* – Participant M, Session 3

> *"I spent a good part of my life working two jobs at a time. At one point I worked four. And I've raised two kids, mostly on my own for a long time and I didn't shy from work. I moved house on my own twice, on my own, moving here to this country with two children. I commuted to London. I put in the energy for things that needed to be done and then I hit a wall and the wall hit me back and I can't get past it"* – Participant O, Session 3

E. Other senses and mobility

Several participants described their sense of smell as fluctuating and unpredictable. At times, smells could be distorted, such as perfume smelling like a burning scent as if someone had just lit a match. These changes in smell occurred randomly and unexpectedly, making the experience unpleasant and challenging to deal with.

Another participant mentioned that Long COVID had significantly affected their life, leaving them feeling disabled as a result. They needed support at home, such as help with shopping and mobility, which they found challenging due to their condition. Additionally, they highlighted the difficulty in accessing services typically available to visibly disabled individuals or those receiving Personal Independence Payments (PIP), for which people living with Long COVID were not eligible.

> *"People who have had the virus for a long time tell of loss of smell and I have no smell whatsoever. So two and a half years on, why doesn't my smell return? It's horrible. Sometimes my husband will say* "Oh that's smells nice out there"*, but I can't smell it. That's a minor thing you forget about, but you can't smell it"* - Participant E, Session 1

> *"Perfume can smell like a burning smell, as if someone's just lit a match or something like that; weird but it's horrible now."* – Participant M, Session 2

F. Daily activity

One participant expressed concern about a significant decrease in their energy levels, feeling exhausted and lacking energy, which was affecting on their ability to engage in activities they used to enjoy, like jet washing the garden. Despite being prescribed antidepressants, which caused side effects like restless leg syndrome and did not address their fatigue, they emphasised that fatigue was not solely due to depression but rather a significant decrease in energy levels.

> *"My handwriting is gone completely, and I can't write. I used to sit and just write just for fun but because of another injury I had I have been working 35 hours a week as a stay-at-home typist."* – Participant N, Session 3

> *"Public knowledge of Long COVID being an actual physical illness that affects you in so many ways and that it's an ongoing disability because you just don't know when it's going to end"* – Participant Q, Session 3

Return to Contents page

Accessing healthcare services

The discussions at the focus group sessions covered a range of experiences of accessing healthcare services. Although most participants reported having had a largely positive experience, there were some who felt they had been treated negatively.

A. Primary care services

Participants expressed frustration with the lack of understanding and support from healthcare providers, as well as the impact Long COVID has had on their daily lives, work, and social activities. Some participants mentioned trying various treatments and therapies, such as physiotherapy, breathing exercises, and holistic approaches like reflexology and reiki, to manage their symptoms. The diverse and debilitating nature of Long COVID and the need for more comprehensive support and recognition of the condition.

Participants explained that they had been offered treatments that included being:

- Prescribed tablets for thyroid issues
- Provided with medication to help with weight management
- Referral to a dermatologist for skin concerns
- Advice on using the right moisturiser for the skin

Return to Contents page

- Discussion about cholesterol levels and potential treatment options
- Suggestions of alternative therapies like reflexology and reiki for pain management.
- Referral for a blood test related to iron levels.

> *"I love alternative therapies, holistic. … Reflexology is really good, reiki is really good; reiki you have to believe in as well, so they don't touch you, then you feel the pain going"* – Participant M, Session 2

> *"About a year, and then from there I've had multiple blood tests, but it's the basic stuff from the GP. Obviously, it's low iron and you know folate and things like that, and thyroid, so they are just the normal generic testing and that's the only blood test they've ever done."* – Participant L, Session 2

Many felt there had been delays in diagnosis, challenges in receiving the right treatment, and the need to advocate for themselves to ensure their symptoms were taken seriously.

Participants shared challenges in getting their Long COVID symptoms recognised and addressed by GPs, with some doctors attributing symptoms to other conditions like menopause or depression. Some participants highlighted the need for more awareness and understanding among healthcare providers about Long COVID as a legitimate and debilitating condition. Additionally, there were mentions of delays in referrals to Long COVID clinics, difficulties in accessing

Return to Contents page

the right support such as physiotherapy, and frustrations with the complexity of the referral process. The document also touched on the importance of patient input in simplifying the referral process and the potential for self-referral to Long COVID clinics.

> *"If this referral is such a long form, maybe you could ask the patient to fill in the form, ask "Do you suffer with …? Do you have any of these effects?" Then you whittle that down when it gets back to the GP, and we've done his work for him effectively."* – Participant S, Session 4

There was a desire for physiotherapy or some form of massage to help with participants' conditions. They mentioned that while psychology support like Cognitive Behaviour Therapy (CBT) was offered, they felt it would not be as beneficial for them at their current stage.

> *"I would absolutely love physio or some sort of massage or anything in that sort of genre. But nothing has ever been mentioned about that, just psychology stuff. They call it Cognitive Behaviour Therapy (CBT) but that's not going to help me now this far down the line."* – Participant L, Session 2

One participant said that, in conversation, their GP had acknowledged challenges with referrals related to Long COVID. They advised that Long COVID diagnosis involved excluding other possible conditions through various tests, which could make the referral process lengthy. The doctor highlighted that GPs need to check multiple factors to ensure they are not missing any treatable conditions before diagnosing Long COVID. Additionally, they discussed the potential for patients to fill in initial questions on the referral form to streamline the process and help narrow down the possibilities before the form reaches the GP.

> *"We've got a fantastic resource and we need to break down this blockage that there appears to be in apparently many GPs."* – Participant D, Session 1

Another participant said that recovery stories and help for Myalgic Encephalomyelitis (ME) could be found on platforms like YouTube, adding that the ME community had been actively sharing information and wisdom, including strategies to regulate cardiovascular systems and brain function. Additionally, they mentioned that individuals with ME have valuable experiences to pass on, which could be beneficial for others dealing with the condition.

> *"When I spoke to my GP about my fatigue, they put that down to the diabetes, that I'm diabetic now, so they say,* "Oh you're now tired because you're diabetic" *so kind of ignore the possibility of Long COVID"* – Participant E, Session 1

Return to Contents page

> *"I had quite an ongoing argument with my GP that I was in the menopause and that everything I was experiencing is due to the menopause. I have a long-standing history of the symptoms of post-viral fatigue from nearly 30 years ago so I know the journey: I know what it's like going into it, I know what it's like coming out of it; but he still insisted that it was the menopause"* – Participant J, Session 1

B. Talking Therapy

A participant explained that when they attended Talking Therapy, they felt "*a bit of a fraud*", because there had been a waiting list and the other people were severely depressed where it was impacting on their life. They felt "*a bit of a fraud*" because they thought, *"I'm not depressed like them"* and felt guilty at taking someone else's place, because the other people in the group were so severely depressed.

Other participants observed that Talking Therapy services were very much around psychology, which was helpful, but did not address their main problems, such as chronic fatigue and loss of taste and smell.

> *"It did help me in a way because I saw that there were other people that were having more difficulties with their daily life than me"* – Participant T, Session 4

> *"When I did these Zoom meetings with IAPT, I actually felt a bit of a fraud, because there was a waiting list and the other people were severely depressed …. I felt quite guilty about it because I thought*

> ' I'm taking someone's place' *because the people were so severely depressed. And I'm not"* - Participant T, Session 4

C. Other therapies

Participants gave accounts of discussing in the Long COVID clinic their experiences with symptoms and treatments. One participant highlighted their significant improvement in breathing after physiotherapy, leading to reduced fatigue levels and enhanced recovery. Another participant described struggles with breathing, fear of breathlessness, and challenges in undergoing tests due to coexisting issues, while a third mentioned memory issues and emphasised the importance of peer support in the Long COVID Clinic, suggesting alternative therapies like acupuncture for recovery. The participants expressed the impact of validation, shared experiences, and non-traditional treatments in their journey towards recovery from Long COVID.

> *"I constantly feel fatigued, muscle aches and pains. I've worked closely with [the NELFT clinic] to help with my breathing, which has helped. But it's like [Participant N] said, you sometimes have to remind yourself* "I'm not breathing right"*. Before I caught COVID, before lockdown, I was a fitness instructor, I was running half-marathons, I was teaching group exercise classes… I've worked closely with [the NELFT clinic], as I've already said, who's helped me immensely. Just by having someone to talk to."* – Participant O, Session 3

Two participants had engaged in different activities to help with their long COVID symptoms. One took part in a programme offered by the English National Opera called "ENO Breathe", where they engaged in voice-training exercises to improve breathing and voice usage. The sessions were led by a non-medical person who encouraged participants to open up, sing freely, and focus on breathing techniques. The sessions had been enjoyable and uplifting, and the participant had experienced improvements in mood and energy levels. Another participant emphasised the importance of mental health support for managing long COVID symptoms. They highlighted the benefits of talking to others who understood their experiences and mentioned learning diaphragmatic breathing techniques to cope with symptoms. Both participants found value in breathing exercises to help alleviate symptoms and improve their well-being.

> *"I'm definitely not Pavarotti in any way shape or form, but it was fun. … by the time that session was over you could actually genuinely see that their faces had changed and that they were not feeling quite so glum. Or so tired. … I enjoyed it. I didn't think I would. I thought it was going to be one of these hippie things, but no, it wasn't. I could imagine us all sitting there singing "Kumbaya", but you know it wasn't that… I find that when I'm getting out of breath during the day, I will sit back and take a moment to breathe properly, which is one of the things they teach"* – Participant S, Session 4

D. The NELFT Long COVID clinic

The Long COVID Clinic framework had had a profound effect on finding a way forward for some participants. They highlighted that the Clinic’s framework was very good and had a profound impact on helping them navigate their condition. This positive impact suggests that the Long COVID Clinic framework provided valuable support and guidance for participants in managing their symptoms and finding a path towards recovery.

Some participants had found cognitive group sessions and physiotherapy helpful in managing their symptoms and improving their quality of life.

> *“I love alternative therapies, holistic. I went to the workshop, and someone very high up in NELFT, in the SPS unit, led it and he said we should look at the whole body and I said,* ‘I love you! I'm a great believer in holistic treatments and I'll do anything to stop the pain’. *Reflexology is really good, reiki is really good; reiki you have to believe in as well, so they don't touch you, then you feel the pain going”* – Participant M, Session 2

> *“I've worked closely with [the NELFT clinic], as I've already said, who's helped me immensely. Just by having someone to talk to”* – Participant O, Session 3

One participant expressed the view that they had been discharged from the Long COVID Clinic without adequate support.

> *" My NHS like record doesn't even state that I have Long COVID, even though the doctor did the referral originally to the long COVID clinic … Now I've had something to say that the Long COVID clinic have discharged me, but I just feel like there's so many different things all the time, but maybe I've not told them about that. I can't remember when I've been to my appointment. I don't know if I've told them everything. I've literally given him a list before and said, "can you just put that all on the system because I literally forget it. So yeah, like the doctors should have it on record."* - Participant R, Session 3

E. The system

One participant, a health and well-being coach, emphasised the individualised nature of addressing symptoms and the importance of collaboration in finding solutions. There was discussion of challenges in accessing the right services, fluctuating symptoms like fatigue and altered senses, and dissatisfaction with online courses and the lack of understanding from healthcare professionals due to the novelty of Long COVID. They highlighted the complexity and uniqueness of Long COVID, the need for personalised care, and the limitations of current healthcare systems in addressing this condition.

> *"… everything is tweaking, and … any illness diabetes, Long COVID, all different, unique, no one's got the same symptoms … there isn't a fix for everyone, it's literally just working with each*

> *other, and seeing what we can do … there's lots of pieces of the jigsaw."* – Participant G, Session 1

The complexity of conditions like Long COVID, diabetes, and other illnesses, was acknowledged, stressing that there is no one-size-fits-all solution. It was noted that those living with Long COVID needed staff to focus on listening attentively, spending time with individuals, and working with them to support the journey towards better health and well-being.

Some participants felt that the healthcare system was slow and broken, struggling to fully understand and address Long COVID. Additionally, participants told of difficulties with accessing services like physiotherapy and pain management. The unpredictable nature of symptoms, such as fluctuating fatigue levels and distorted sense of smell, complicated the provision of the right support. Participants were disappointed that courses and services did not meet their needs effectively. Overall, they emphasised the need for personalised and understanding approaches to support individuals living with Long COVID.

Participants discussed their struggles with Long COVID not being recognised as a disability, the challenges they faced at work, their symptoms, interactions with healthcare providers, and their desire to return to full-time work. There was frustration over their medical records not reflecting their Long COVID

Return to Contents page

diagnosis, the changing nature of their symptoms and difficulties in communication with healthcare providers.

> *“The system moves slowly; the system is scared and the system is broken. I’m not downplaying what they do because they do a marvellous job and I never once failed to clap for them. But the problem is this is so new, that most of the doctors haven't got their heads around it”* – Participant M, Session 2

F. Vaccination

A vulnerable participant pointed out that they were entitled to be vaccinated. They explained that, when they were due to have the vaccination, and although they were needle-phobic but because they did not want to get Covid again, they went to the surgery. Because of their medical background, this participant needed to avoid having the Pfizer vaccination – but that was the only vaccine available at the surgery. When the participant asked where they could find a different vaccine, the surgery staff decline to help and told them “*It's actually not our problem, what you need to do is phone 111*”, which they did but the participant found them equally unhelpful. Eventually, this individual had to phone around many clinics, without success, with the result that they never had that vaccination. Their experience has been that no one can advise where a particular version of the vaccine is available.

> *"I had the AstraZeneca which put me in A&E with extremely high heart rate and my blood pressure all over the place and they actually thought that I had COVID. But I tested negative, but they wouldn't allow me back"* – Participant O, Session 3

> *"After suffering the side effects of the first vaccine, I was told that my immune system was poor and that I needed to have the 2nd vaccination so, stupidly, I had the second one - and went through the same process all over again. You probably think I'm mad, but you are listening to advice that you are given by medical professionals and then on the booster which was the Pfizer a day later or two days later. I was not very well that evening"* – Participant Q, Session 3

Return to Contents page

Support needed

Participants shared their struggles with accessing prompt medical care, lack of support services, challenges in getting diagnosed, meeting dismissive attitudes from healthcare professionals, and the impact of Long COVID on their daily lives. They also highlighted the need for more comprehensive support, better understanding of Long COVID in society, and the importance of respectful and inclusive treatment from healthcare providers.

One participant mentioned experiencing various side effects after receiving the AstraZeneca vaccine, which included vision issues, body rashes, balance problems and bodily tremors.

> *"… the AstraZeneca … put me in A&E with extremely high heart rate and my blood pressure all over the place and they actually thought that I had COVID. But I tested negative"* – Participant O, Session 3

> *"… the hospital wasn't sure whether it was to do with potential COVID or blood clots, or my body's just reacting to the vaccine. I had many strange symptoms. I mean, probably 30 or more. There was a stage where I couldn't see. I had vision issues, body rashes. I mean it was horrendous."* – Participant Q, Session 3

Another participant experienced adverse effects after receiving the vaccinations. They had a negative reaction after receiving the booster vaccine, feeling unwell that evening. Additionally, they described experiencing balance problems, tremors, high blood pressure, and heart issues. They also mentioned that their immune system was considered poor, leading to difficulties with the vaccinations and later health issues.

> *"No nothing at all, No support whatsoever"* – Participant L, Session 2
>
> *"They spoke to us as adults. And, you know, that's rare to find. I used to work in the NHS. It's rare to find that kind of modern approach. I still don't come across it very much.* 'You're still smoking too often', *as if you're the patient who knows nothing, but they were very, very good. The sessions were good, the support was good. The after aftercare has been excellent."* – Participant P, Session 3

Return to Contents page

Peer support needs

Most participants favoured the idea of a dedicated peer support group being set up for people living with Long COVID.

Participants expressed varying opinions on peer support, highlighting the importance of a positive approach, professional input, and the need for diverse experiences and information sharing within support groups. Some participants found existing support groups inadequate for their Long COVID symptoms, while others appreciated the benefits of structured support like the Long COVID clinic. Additionally, experiences with mental health services like IAPT were shared, with one participant having felt out of place, having not experienced the severe depression others in the group were describing. Overall, the participants emphasised the need for tailored and inclusive support structures for individuals dealing with Long COVID and mental health challenges.

> *"You know, talking at CBT just sort of helps you manage mentally with your symptoms every day, but they don't help with the anger that you feel over how you are now, and the emotional side of it. So talking to other people going through the same thing would help, I think."* – Participant L, Session 2

Participants believed that their condition was not as impactful on their life compared to others in the Talking Therapy groups and felt they were taking someone else's place who might have needed the support more than they did.

> *"As to peer support groups, I haven't had those because unfortunately the ones I've been sent to have all been focused on anxiety and depression and none of my symptoms are covered"* – Participant O, Session 3

> *"I am in favour of peer support provided there is a positive approach. When people get together and we all have the same symptoms, you can get yourself into a non-productive cycle as well and then it doesn't become peer support. A replication of something similar to what the Long COVID group had you know where you have a mixture of peer support, but in a framework of some kind of professional or helpful input … You need people who have time to commit to that"* – Participant P, Session 3

Conclusions

This report highlights the continuing impact of Long COVID on individuals in Havering, ranging from mild inconveniences to severe debilitation. It emphasises the diverse and persistent nature of symptoms experienced by individuals, affecting various aspects of their daily lives, work, and social interactions. Participants also shared challenges in accessing healthcare services, including delays in diagnosis, difficulties in receiving appropriate treatment, and the need to advocate for themselves to ensure their symptoms were taken seriously. Some participants mentioned experiencing dismissive attitudes from healthcare professionals, delays in referrals to the Long COVID Clinic, and feeling frustrated by the complexity of the referral process.

Participants' comments underscored the need for more comprehensive support for individuals living with Long COVID, better understanding of the condition in society, and respectful treatment from healthcare professionals. They expressed the importance of tailored and inclusive support structures, highlighting the impact of Long COVID on their mental well-being, daily activities, and overall quality of life.

Some participants found existing support groups inadequate for their Long COVID symptoms, with a need for more positive

Return to Contents page

approaches, professional input, and diverse experiences within support groups to effectively address the challenges faced by individuals dealing with Long COVID and mental health issues.

One participant also faced challenges in accessing specific vaccines due to medical conditions and adverse reactions which had a negative impact on that individual's health.

Participants described the slow and broken nature of the healthcare system in addressing Long COVID, emphasising the need for:

- personalised care
- attentive listening from healthcare professionals, and
- collaborative efforts to support individuals living with the condition

There were frustrations over the lack of recognition of Long COVID as a disability and the complexities involved in navigating the healthcare system.

Suggestions for action

The report identifies a need for increased awareness, improved support services, streamlined referral processes, enhanced understanding among healthcare professionals, and the establishment of more tailored and inclusive support structures to address the multifaceted challenges posed by Long COVID in the community.

Based on participants' comments, the following suggestions for action are put forward for consideration:

1 Prompt Medical Care:

Participants highlighted the importance of accessing prompt medical care to address their Long COVID symptoms effectively and receive timely diagnoses and treatments.

> *"… it's about finding the knowledge where it exists, because if we go to our GP's and find that we've got to wait three to four weeks for an appointment and then we're told that we need a triple appointment, which is actually only 15 minutes long and then we go in with our list. We have bullet points to talk about as fast as we can, when you got brain fog and then you come out and find you've got forgotten something, and you have to wait another three weeks before you can add that thing! It's very desperate. I try very hard to squeeze what I can say in but*

> *… the reaction is "I haven't got time to do it now," and the attitude is "You are wasting my time". – Participant F, Session 1*

2 Understanding and Recognition:

There was a strong desire for healthcare professionals to understand and recognise Long COVID as a legitimate and debilitating condition, ensuring that symptoms are taken seriously and appropriate support is provided.

> *"… they say, "Oh you're now tired because you're diabetic," so kind of ignore the possibility of Long COVID" – Participant E, Session 1*

> "*I had quite an ongoing argument with my GP that I was in the menopause and that everything I was experiencing is due to the menopause, and I'm like "That's not menopause". I have a long standing history of the symptoms of post-viral fatigue from nearly 30 years ago so I know the journey:"* – Participant J, Session 1

3 Comprehensive Support Services:

Participants emphasised the need for more comprehensive support services tailored to the diverse and persistent nature of Long COVID symptoms, including access to treatments, therapies, and interventions that address their specific needs.

> *"I also feel aware of that the world doesn't know about it do they? So everybody's scrabbling in the dark with the varying*

Return to Contents page

> *symptoms. Listening to you all, I'm thinking about bits of myself that, and I had not put together until now"* – Participant B, Session 1

> *I went in with a list of diseases or illnesses or all new things I could think of, so I've done his job for him and he said "OK, we'll test for all these things, but I don't think anything will come back. If not, we'll say it's FND [a Functional Neurological Disorder]". They are so quick to say "It's all up here" without doing full testing or research.* – Participant L, Session 2

4 Advocacy and Validation:

Individuals expressed the need for advocacy to ensure their symptoms are recognised and addressed by healthcare professionals, as well as the importance of feeling validated in their experiences with Long COVID.

> *"… they're all things that are never going to be supplied by the Council or any other department. I need a career of some sort to come and do things at home for me that I can't do, there's a whole list of needs. It sounds like basically you need a celebrity lifestyle to fund it"* – Participant L, Session 2

> *"I'm not getting a great deal of health support from having tablets prescribed to me, so I've taken my healing into my own hands by using therapeutic methods like acupuncture, which has a profound effect on keeping me steady. But it's very expensive and I feel it's a real shame that that's not available more widely to use as an alternative"* – Participant Q, Session 3

5 Inclusive Treatment:

Participants highlighted the importance of receiving respectful and inclusive treatment from healthcare professionals, emphasising the need for personalised care and understanding of the complexities of Long COVID.

> *“Long COVID isn't recognised as a disability. It's not covered under the Disability Act. I've had many arguments within my workplace as I have a long-term illness. I'm quite lucky that my line manager is very helpful, however I've had to go backwards and forwards to our occupational health, HR, etc fighting to be listened to in work because it's not recognised as a disability” – Participant O, Session 3*

6 Mental Health Support:

There was a call for mental health support to help individuals cope with the emotional impact of Long COVID, including strategies to manage anxiety, depression, and the challenges of living with a chronic health condition.

> *“… because I think that's the best help for the mental health, I think. You know, talking at CBT just sort of helps you manage mentally with your symptoms every day, but they don't help with the anger that you feel over how you are now, and the emotional side of it”* – Participant L, Session 3

Return to Contents page

7 Peer Support Groups:

Many participants favoured the idea of dedicated peer support groups for individuals living with Long COVID, emphasising the benefits of sharing experiences, receiving peer input, and building a supportive community.

> *"… there's so much information out there that's not necessarily in the mainstream media that could have a profound sharing in a peer group, especially people sharing, for example acupuncture, therapeutic things that are actually enabling us to live our life"* – Participant Q, Session 3

8 Streamlined Referral Processes:

Participants identified the challenges of navigating complex referral processes to access specialised Long COVID clinics and services, highlighting the need for simplified pathways to ensure timely and appropriate care.

> *"If this referral is such a long form, maybe you could ask the patient to fill in the form, ask "Do you suffer with …? Do you have any of these effects?" Then you whittle that down when it gets back to the GP, and we've done his work for him effectively"* – Participant S, Session 4

9 Tailored Care:

There was a consensus on the importance of receiving tailored and individualised care that addresses the unique symptoms and challenges faced by individuals living with

Long COVID, recognising the need for personalised approaches to support recovery and well-being.

> *"When you go to the doctors, you do feel like you're banging your head against the wall because you're saying all this stuff to them and they're just not getting it, just like it's gone over their heads but to talk to people that actually understand what you're going through would be amazing"* – Participant L, Session 2

Overall, individuals with Long COVID expressed a range of support needs, from medical care and recognition of their condition to emotional support, advocacy, and access to comprehensive services that address the multifaceted impact of Long COVID on their lives.

These suggestions reflect the participants' insights into the types of support structures that would be beneficial for individuals living with Long COVID, emphasising the need for inclusive, personalised, and holistic approaches to address the multifaceted impact of the condition on their lives.

Return to Contents page

Acknowledgements

Healthwatch Havering thanks all the participants in the four focus group sessions for their full frank contributions to the discussions now reported. Their willingness to be open about their circumstances greatly assisted the identification of the issues facing them and their experiences, both of the effects of Long COVID itself, and the way in which they perceived the health care system has (or has not!) supported them.

Participation in Healthwatch Havering

Local people who have time to spare are welcome to join us as volunteers. We need both people who work in health or social care services, and those who are simply interested in getting the best possible health and social care services for the people of Havering.

Our aim is to develop wide, comprehensive and inclusive involvement in Healthwatch Havering, to allow every individual and organisation of the Havering Community to have a role and a voice at a level they feel appropriate to their personal circumstances.

Members

This is the key working role. For some, this role will provide an opportunity to help improve an area of health and social care where they, their families or friends have experienced problems or difficulties. Very often a life experience has encouraged people to think about giving something back to the local community or simply personal circumstances now allow individuals to have time to develop themselves. This role will enable people to extend their networks, and can help prepare for college, university or a change in the working life. There is no need for any prior experience in health or social care for this role.

The role provides the face-to-face contact with the community, listening, helping, signposting, providing advice. It also is part of ensuring the most isolated people within our community have a voice.

Healthwatch Havering Friends' Network

Join our Friends' Network for regular updates and other information about health and social care in Havering and North East London. It cost nothing to join and there is no ongoing commitment.

To find out more, visit our website at https://www.healthwatchhavering.co.uk/advice-and-information/2022-06-06/our-friends-network-archive

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Return to Contents page