Raising the profile of the impact of Long Covid on Croydon residents

Press release: 29 June 2022

- **Long Covid is a series of symptoms that last more that 12 weeks after having contracted Covid-19, with many feeling the effects of this a year later.**
- **Around 1 in 4 had symptoms but not a diagnosis, with fatigue, anxiety, and headaches the most severe symptoms, 74% said it affected their mental health and 75% quality of life, yet 53% had not received any help and relied on friends and family.**
- **Developing a better screening process, creating better pathways between GPs and consultants, along with dedicated community support for those with Long Covid would help those cope much better.**

Long Covid is an informal term that is commonly used to describe signs and symptoms that continue and develop after an acute infection of Covid-19. It usually presents with varied symptoms that can change over time commonly respiratory and cardiovascular symptoms, as well as fatigue, fever, and pain as well as anxiety. As a new condition, there is no test or clear pathway for Long Covid. This makes the condition difficult to identify and treat and there is a variation in diagnosis between clinicians. Many of the symptoms can be like other conditions, but research is developing to suggest that Long Covid is a condition in its own right.

Healthwatch Croydon undertook a survey between July and November 2021 to ask those who had experienced Long Covid symptoms to share their experience. This survey was aligned with similar surveys undertaken by Healthwatch in South West London within this period.

These are our findings based on sixty-two detailed responses from the survey:

- **Despite having the symptoms of Long Covid for some time, 1 in 4 had not had a diagnosis:** 37% respondents had been diagnosed with Long Covid, and

23% had Long Covid symptoms but had not yet been diagnosed. 43% had not had health conditions before contracting Covid illustrating the impact that Long Covid can have on previously healthy people.

- **While most started the patient journey with a GP it was a clinic, hospital, or consultant where they got diagnosed and where patients received a better response:** Only two respondents were diagnosed by a GP and had a positive experience. Eight were diagnosed by the hospital, three at a clinic and two by a consultant. It is likely GPs are not able to give a diagnosis but will refer therefore accounting for the negative or neutral experience felt by the patients here.

- **Most respondents had symptoms for a considerable time and were still experiencing these at the time of the survey**: 34% of respondents had Long Covid symptoms for 12 months or more, 31% had experienced symptoms for 6-8 months, 23% for 9-11 months. 85% of respondents were still experiencing Long Covid symptoms with 11% unsure, and just 3% stating they were not experiencing symptoms.

- **Fatigue, anxiety, and headaches were the most severe symptoms and muscle pain was the highest recorded moderate symptom along with fatigue, breathlessness, memory, and concentration:** 40% experienced severe fatigue, 31% had severe anxiety, and 19% experienced severe headache. 45% reported moderate muscle pain, with 44% reporting moderate fatigue. 41% experienced moderate breathlessness with 35% with moderate problems with memory and concentration.

- **Most had their emotional wellbeing or mental health affected by Long Covid:** 74% said living with Long Covid negatively impacted their emotional wellbeing or mental health. 24% participants reported anxiety, and 22% reported depression and 11% reported both anxiety and depression.

- **When receiving support, most got this from friends and family:** 53% had not received any help except from friends and family. The GP scored most highly with 27% reporting that they received help from their doctor.

Outpatient care at a hospital was reported by 21%. 47% said yes that they did have a carer, and 53% said no. This suggests over half of those responding did not previously need care support.

- **Most felt their quality of life was impacted:** 75% felt that their quality of life was impacted with 37% reported that their work/school life was affected, 32% of respondents felt that their relationships were affected and 20% said caring or parenting roles were impacted.

These are our recommendations which are relevant to providers and commissioners:

- **Develop a better screening process**: Low and inconsistent levels of diagnosis compared with symptoms point to the need for a better and more consistent screening process.
- **Create better pathways between GPs and consultants and build wider multi-disciplinary teams:** Most patients begin their patient journey with a GP but need to see a consultant to get diagnosed. Better pathways need to be developed to refer patients swiftly and easily which can involve a wider range of health professionals to support patients from physical conditions to mental health.
- **Deliver dedicated community support services for those with Long Covid:** People who were previously well have been affected by this long-term condition, usually with little formal support. A package of support needs to be created, to enable people to manage their conditions and improve their quality of life including peer-led support groups to help those on their diagnosis and care journey.
- **Focus on supporting family and friends:** Since many have relied on family and friends for support, focus support packages to help family and friends.

- **Ensure those living on their own get the care they need:** Those living on their own may not have any access to care from family and friends and can be suffering alone. There is a need to ensure this information is collected at the screening process to support them with recovery and give them enhanced support.

- **Gather more insight about who is most affected by age, gender, and ethnicity:** Our survey small was small, but suggests certain demographics were affected more than others, create regular insight through surveys. focus groups and interviews to create continued conversations with patients to ensure services meet patient need.

You can view the report here:

https://www.healthwatchcroydon.co.uk/learn-more/our-reports/

Gordon Kay, Healthwatch Croydon Manager, said: "One of the many legacies of Covid-19 epidemic has been the presence of Long Covid. Many previously healthy Croydon residents have found that they have continued conditions brought on by contracting Covid-19. This survey raises the profile at local level of the impact this is having on people, many of whom previously did not need support or care. We particularly concerned about the impact on quality of life and the emotional health and wellbeing of suddenly having a long-term condition of which little is known.

"While we know that services are responding in so many ways to the impact of Covid-19, Long Covid needs to be given more profile and recognition and better pathways for those suffering to get the support they need. This report shows also how important friends and family are in helping patients. We are glad our data is being shared more widely as part of project with our colleagues across South West London Healthwatch so that something can be planned at an integrated care level as well as for Croydon."

Matthew Kershaw, Trust Chief Executive and Place Based Leader for Health, said:

“Croydon was one of London’s hardest hit boroughs, with 100,000 people testing positive for COVID-19 since the start of the pandemic – broadly a quarter of the local population. Our aim is to get as many people back to full health as possible, but from what is now known about the virus, many may face a long road to recovery.

“With Croydon GPs alongside our expert hospital teams and neighbouring trusts, we are providing continuing treatment and support for post-COVID patients, including those who had prolonged stays in intensive care. We’re also reaching out to offer more care at home for patients that didn’t need treatment in hospital for the virus, but who are now struggling to manage COVID’s after effects, including chest pain, chronic fatigue and brain fog.

“This Healthwatch report is a helpful reminder for the prolonged impact COVID-19 can have. This is something we are acutely aware and one that we working on to wrap our care and support around people in our community.”

Rachel Flowers, Croydon’s Director of Public Health, said:

“Today’s report from Healthwatch Croydon provides useful insight into how we can provide the best care and support for those whose lives continue to be impacted by Covid. We want to commend the dedication of our local NHS staff, social care colleagues and many others who worked long and hard during the pandemic to protect people in Croydon from the virus and to stem the rise of infections.”

Editor's notes

Healthwatch Croydon is here to improve the experience that Croydon people have when they need to use health and social care services. We believe that the best way to do this is by listening to patients and service users.

There is a local Healthwatch in every local authority area in England.

Our role is to make sure that that local health and social care services, and the local decision makers, put the experiences of people at the heart of their care.

We are a statutory body - this means that we have a legal status to exist within the Health and Social Care Act 2012. This means decision-makers should listen to us when we give them feedback and make suggestions.

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