

People's Experience of Long COVID in North Central London



Background

- Long COVID is a new and evolving condition that can greatly impact the health and quality of life of many people.
 - Long COVID presents itself through a wide range of clustered symptoms.
 - Data from the Office for National Statistics show that an estimated 1.7 million people self-reported experiencing Long COVID symptoms as of April 2022.
 - University College London Hospitals (UCLH) provides the Post-COVID Specialist Clinic service for residents across North Central London (NCL).
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What We Did

- Five Healthwatch organisations across NCL worked in partnership together on a joint NCL Long COVID project.
 - **Aims of the project:**
 - To capture local people's experiences of Long COVID in order to identify any gaps in current provisions.
 - To support the better development of services and systems to help local people to manage their symptoms.
 - **Hybrid methodology:**
 - Anonymous online survey
 - 1-2-1 interviews
 - Community focus groups
 - Survey respondents had the option to participate in a follow-up 1-2-1 interview to enable us to gather detailed in-depth qualitative data.
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What We Did

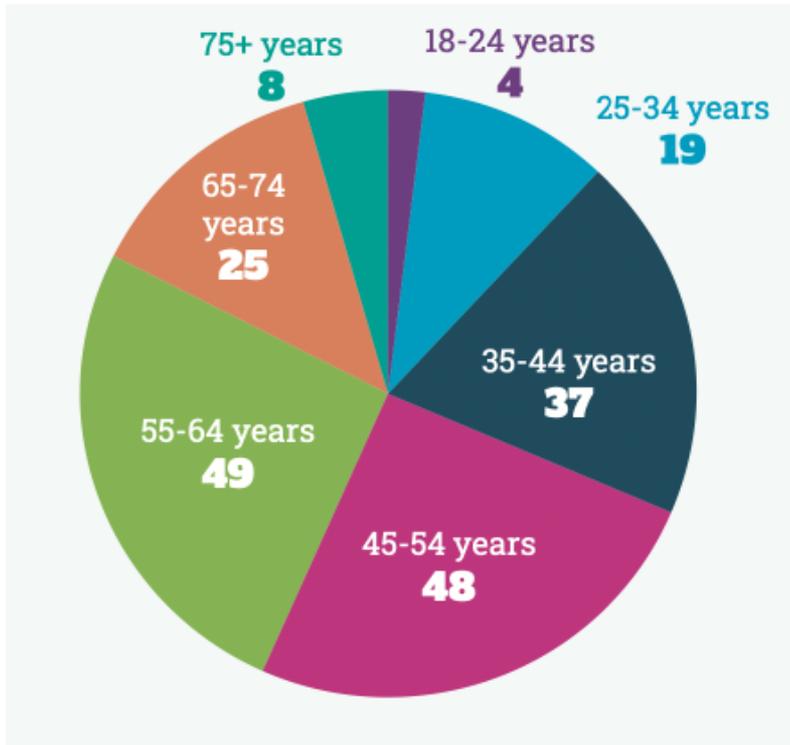
- Each Healthwatch worked with local voluntary sector organisations to broaden their reach.
- In total, we gathered 300 local peoples' experiences of Long COVID across NCL.
- Data was collected from September 2021 to February 2022.

Local Healthwatch	Survey Reponse	1-2-1 Interviews	Focus Groups	Community Event/Others
Healthwatch Barnet	63	18	2	1
Healthwatch Camden	79	5	0	3
Healthwatch Enfield	53	0	0	0
Healthwatch Haringey	21	4	0	0
Healthwatch Islington	38	14	1	0

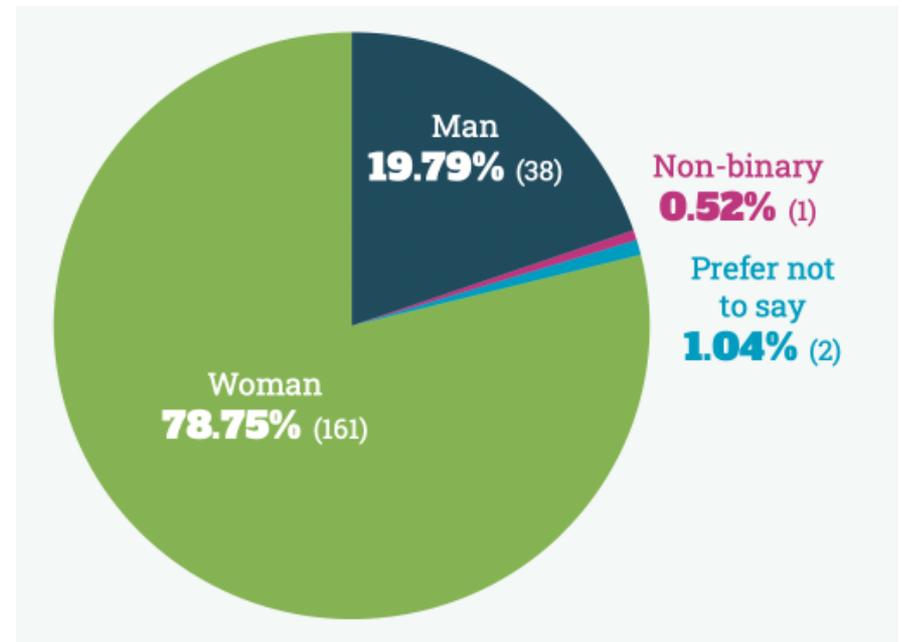


Respondent Profiles

- We gathered demographic data from approximately 190 of 254 respondents.



Age



Gender

Respondent Profiles

Ethnicity

Arab	1
Asian / Asian British: Bangladeshi	17
Asian / Asian British: Indian	7
Asian / Asian British: Pakistani	2
Asian / Asian British: Any other Asian / Asian British background	3
Black / Black British: African	9
Black / Black British: Caribbean	8
Black / Black British: Any other Black / Black British background	1
Mixed / Multiple ethnic groups: Black African and White	1

Mixed / Multiple ethnic groups: Black Caribbean and White	1
Mixed / Multiple ethnic groups: Any other Mixed / Multiple ethnic background	2
White: British / English / Northern Irish / Scottish / Welsh	79
White: Irish	2
White: Any other White background	31
Polish	2
Romanian	1
Turkish	3
Another ethnic background	2

Disability	Number	Percent
Yes	47	25%
No	131	69%
Prefer not to say	12	6%

What We Found



Key Findings

- **Theme 1 - Impact on Health**

- Physical health
- Mental health and wellbeing
- 73% of respondents reported that they had been living with Long COVID for 6 months or more, with various symptoms affecting their physical and mental health.

My mental well-being is pretty bleak because of the gaslighting and lack of support I received. I can manage mentally with the ups and downs of Long COVID but being denied adequate support is hard to bear. I feel useless and hopeless.

Camden Resident

Key Findings

- Theme 2 - Impact on Life

- Employment and job security
- Home life
- Symptoms caused challenges in ability to work, leading to some respondents having to reduce their working hours, voluntarily stop working or be made redundant.
- This had an adverse impact on some respondents' household finances.

I've had to move home, I was in rented accommodation. I couldn't afford to stay there, I also couldn't look after myself and remain independent. So around the house, I rely on other people to help me like they do the shopping, cooking cleaning. I have help washing as well, sometimes on bad days. So it's been a huge life change from being very independent to relying on people around me for support.

Barnet Resident

Key Findings

- **Theme 3 - Experiences With the Health Care System**
 - Accessing the Long COVID Pathway
 - Healthcare support and referrals
 - Useful interventions
 - Diagnosis
 - GP knowledge

I have been struck by the lack of knowledge re Long COVID and the lack of compassion shown by some GPs. They have been dismissive, lacking in any management plan and keen to psychologise my symptoms. I've had to push for the referrals. I worry about those patients who are not able to advocate for themselves.

Haringey Resident

Key Findings

- **Theme 4 - Moving Forward**
 - Improve GP's knowledge
 - Recognise patients' symptoms and their impact
 - Improve awareness of the support already available
 - Improve access to primary care
 - Improve access to specialist care where needed
 - Enable continuity of care
 - Share self-management techniques early
 - Peer support groups

There needs to be regular examinations of how we're doing - just to check that our cognitive skills are still intact. I haven't had any support with coping with brain fog, anxiety, tearfulness and worry etc.

Enfield Resident



Recommendations

Recommendations - NHS

Primary Care

- Improve access to GP services and face-to-face appointments, for which there are already existing reports and insight from all five NCL Healthwatch.
 - Increase training and support for primary care clinicians so they can be better informed on Long COVID and its symptoms. This will also help identify patients with potential Long COVID.
 - Build awareness of local support and treatment already available for patients through a multi-platform communications campaign.
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Recommendations - NHS

NCL CCG

- Ensure there is more consistency in people's experiences accessing the Long COVID pathway taking into account patients' physical, mental and social needs.
 - Ensure at the point a patient is referred for Long COVID support the Long COVID Pathway is explained and communicated to them in an accessible method.
 - Ensure all patients on the Long COVID pathway are clear about how they will be followed up after their first appointment, including planned and patient-initiated options.
 - Patients who are diagnosed with Long COVID or referred for further support should be given immediate access to applicable self-care and self-management resources regardless of the 12-week NICE guidance.
 - Invest in the development of local peer support groups for Long COVID.
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Recommendations - NHS

- **Long COVID Clinic & Community Teams**
- Ensure all patients on the Long COVID pathway understand how to contact the clinical team responsible for their care accurately through telephone and email.



Recommendations - Councils

- Local Education Authorities should work proactively with teachers through education and training to support families whose children are absent from school due to Long COVID.
- Local Public Health teams should continue to monitor data and conduct an ongoing needs analysis of Long COVID in communities to inform how NCL CCG can make the Long COVID services more equitable and address inequalities.
- Local Public Health teams should publish their data on Long COVID to make it more visible.



Recommendations - Employers

- Human resource departments of employers in North Central London statutory services, such as NHS Trusts, Councils and the NCL CCG, working with the NCL's Long COVID Vocational Rehab Service, should recognise and adequately accommodate employees diagnosed with Long COVID through flexible working policies.

