A woman with long dark hair is sitting on a light-colored sofa, looking down and holding her hand to her forehead in a gesture of distress or exhaustion. She is wearing a dark ribbed sweater over a white collared shirt.

People's Experience of Long COVID in North Central London

April 2022

Background

Long COVID is a new and evolving condition that can greatly impact the health and quality of life of many people. The precise causes of Long COVID are not yet known and the recovery time varies for each patient. More research is required to develop a standardised treatment pathway from diagnosis to treatment and management of the condition.

There is currently no agreed clinical definition, however the National Institute for Health and Care Excellence recommendation is that 'Ongoing symptomatic COVID-19' be used when symptoms continue after 4 weeks of contracting COVID-19 and are not explained by an alternative diagnosis; and 'Post-COVID-19 syndrome' is used when symptoms continue beyond 12 weeks or newer symptoms develop. Both are commonly called Long COVID by laypeople.

Long COVID presents itself through a wide range of clustered symptoms. A study conducted by University College London¹ identified Long COVID patients self-reported over 200 symptoms across 10 organ systems². The most recent data from the Office for National Statistics show that an estimated 1.5 million people self-reported experiencing Long COVID symptoms as of 31st January 2022³.

To tackle the debilitating impact of the condition, the Long COVID NHS Plan for 2021/22 outlined an investment of £100 million to support patients. There are now approximately 90 Post-COVID Specialist Clinics across England that support patients where previous medical care did not aid their recovery. These specialist clinics provide physical, cognitive and psychological treatment. The plan

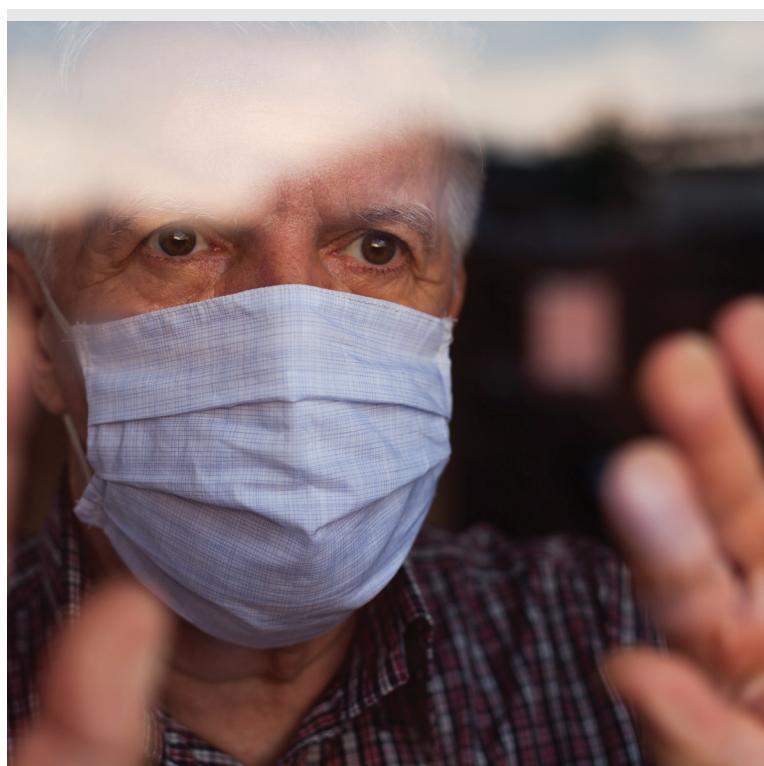
also outlines the establishment of paediatric hubs to support children and young people suffering from Long COVID.

University College London Hospitals (UCLH) provides the Post-COVID Specialist Clinic service for residents across North Central London (NCL). The chart below shows the Long COVID patient pathway.

¹ www.nice.org.uk/guidance/ng188/resources/COVID19-rapid-guideline-managing-the-longterm-effects-of-COVID19-pdf-51035515742

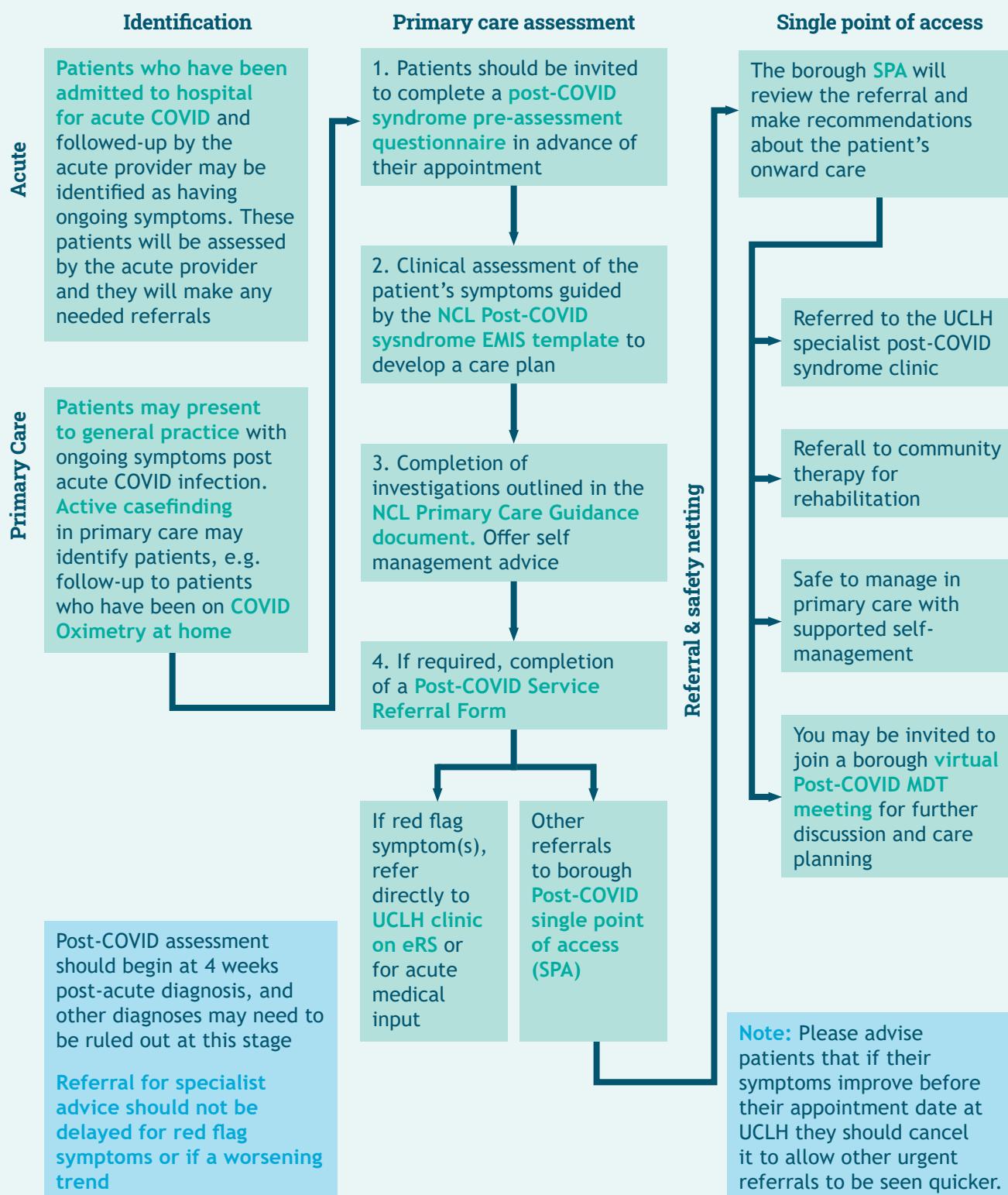
² www.ucl.ac.uk/news/2021/jul/identification-over-200-long-COVID-symptoms-prompts-call-uk-screening-programme

³ www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/3march2022



North Central London Integrated Post-COVID Syndrome Service

NCL Patient Pathway



What we did

The five Healthwatch organisations across NCL (Healthwatch Barnet, Healthwatch Camden, Healthwatch Enfield, Healthwatch Haringey, and Healthwatch Islington) agreed in the summer of 2021 to work in partnership together on a joint NCL Long COVID project.

The core aims of this project were:

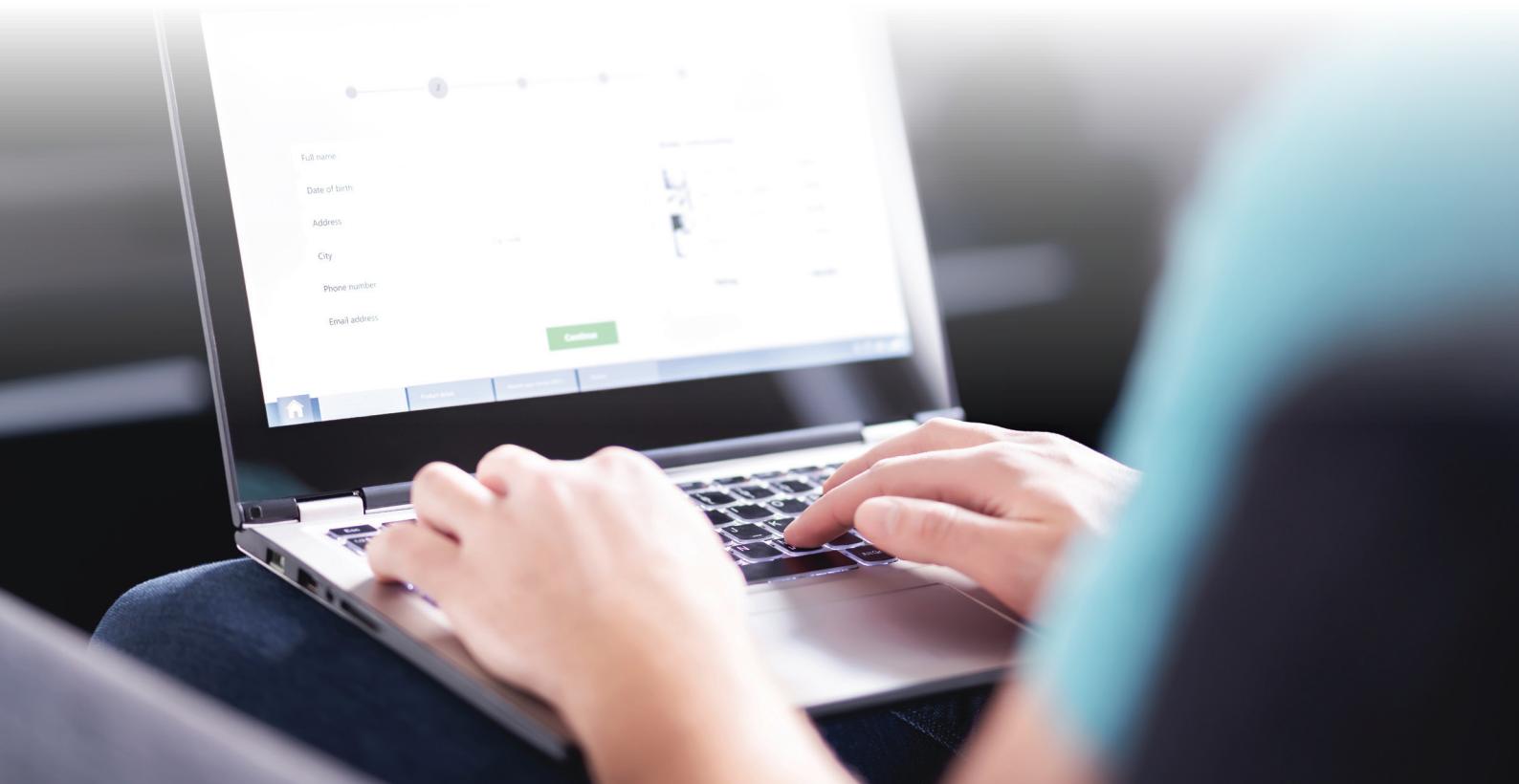
- To capture local people's experiences of Long COVID in order to identify any gaps in current provisions.
- To support the better development of services and systems to help local people to manage their symptoms.

To gather insight on local NCL residents' experiences of living with Long COVID, we jointly agreed on a hybrid methodology: an anonymous online survey, 1-2-1 interviews and 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.

We also shared our draft survey with the North Central London Clinical Commissioning Group, who developed the local patient pathway, and we implemented their feedback in our online survey.

Each Healthwatch worked with local voluntary sector organisations to broaden their reach and gather robust responses, and we entered every person who took part into a prize draw to win one of five £50 gift vouchers to increase engagement.



We also engaged and shared our survey with local press and statutory healthcare services that support people with Long COVID.

We aimed to gather experiences of people across the whole treatment pathway, from those seeking support in primary care from their GP, those receiving support in the community, those who required support from a specialist Long COVID clinic, and those who had never reached out for help and were managing symptoms on their own.

The survey covered the impact of Long COVID on patients' lives, their physical and mental health, access to NHS treatment, experience with healthcare professionals and suggestions for improvement. Subsequent 1-2-1 interviews and focus groups loosely followed a similar structure of questions. In total, we gathered 300 local peoples' experiences of Long COVID across NCL. The data from this report was collected from September 2021 to February 2022.

Local Healthwatch	Survey Response	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



Summary of findings

Impact on Health

Physical Health
Mental Health & Wellbeing

Impact on Life

Employment & Job Security
Home Life

Experiences with the Health Care System

Accessing the Long COVID Pathway
Healthcare Support & Referrals
Useful Interventions
Diagnosis
GP Knowledge

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



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 multi-platform communications campaign.

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.

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.

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.

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.

Healthwatch Barnet

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 healthwatchbarnet.co.uk

Healthwatch Enfield

 Community House
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 020 8373 6283

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Healthwatch Islington

 6-9 Manor Gardens
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 07538 764436

 healthwatchislington.co.uk

Healthwatch Camden

 85-87 Bayham Street
Camden
London NW1 0AG

 020 7383 2402

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Healthwatch Haringey

 Tottenham Town Hall
Town Hall Approach Road
London N15 4RX

 020 8888 0579

 healthwatchharingey.org.uk

healthwatch

Barnet Camden Enfield Haringey Islington