



People's experience of Long COVID in Haringey

June 2022

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1. Introduction

The following report provides an important snapshot of the challenges faced by Long COVID patients in Haringey, and makes recommendations to improve the local support and services available to them.

Background

The five Local Healthwatch within North Central London (Haringey, Enfield, Barnet, Islington, and Camden) agreed to work together, in partnership, on a Long COVID project.

We aimed to capture local people's experiences of Long COVID:

- to identify any gaps in current service provision, and
- improve local services to better help and support local people living with Long COVID.

Long COVID is a new and evolving condition that has greatly impacted the health and quality of life of many Haringey residents.

National trends suggest there should be more than 3,000 Haringey residents diagnosed with Long COVID.

The Long COVID patient pathway developed by North Central London (NCL) Clinical Commissioning Group (CCG) has aided the recovery of many patients experiencing this debilitating illness. But there are many lessons to be learnt from the lived experience of Long COVID patients, who have, by necessity, had to become experts by experience. Like with any new condition or service, there is room for improvement to enable patients to access the treatment they require.

2. Methodology

Healthwatch Haringey carried out an online survey and engaged in 1-2-1 interviews with residents.

- For the five Healthwatch report we used different methods to capture people's experiences:
 - An online survey
 - 1-2-1 interviews, and
 - Community focus groups.
- The 1-2-1 interviews and community focus groups enabled us to gather more detailed in-depth qualitative data, exploring themes and issues highlighted in the online survey.
- We gathered experiences of people across the whole treatment pathway, from those seeking support from their GP to those receiving support from University College London Hospital (UCLH)'s specialist Long COVID clinic.
- 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.
- We gathered 300 local peoples' experiences of Long COVID across North Central London.
- The joint report by the five local Healthwatch was published in April 2022 and is available here https://bit.ly/Healthwatch_Long_COVID_Report_April22
- This is a supplementary local report which focuses on the experiences of Haringey residents. This Healthwatch Haringey Long COVID report includes:
 - data from the 21 respondents to the online survey who were Haringey residents, and
 - 1-2-1 interviews with four Haringey residents who completed the survey.

3. Executive Summary

Impact of Long COVID on health and wellbeing

Long COVID has had a huge impact on people's physical and mental health and wellbeing and on their day-to-day lives.

Employment and finances

- 15 out of 21 respondents (71%) said Long COVID had impacted on their ability to work or the number of hours they can work.
- Two people were made redundant and one accepted voluntary severance (along with others in their firm who also had Long COVID).
- Seven out of 21 respondents (33%) said their finances were affected.

Recommendations

- Statutory services (Haringey Council, NCL CCG, and NHS Trusts) should model being a good employer for people living with Long COVID. Their HR departments should ensure reasonable adjustments are made, and flexible working arrangements explored, to ensure people can keep their jobs and continue to work.
- Information, help and support should be provided to people living with Long COVID to ensure they are able to access any benefits they are entitled to.

Physical health

- 16 out of 21 (76%) respondents said their physical health had been impacted by Long COVID.
- They reported significant, wide ranging, multiple and severe physical health impacts. These included fatigue / exhaustion, stomach problems, heart palpitations, headaches, brain fog, aching limbs, insomnia, pain in muscles and bones, severe back pain, joint pain, decreased mobility, and loss of taste and smell.

Mental Health

- 14 out of 21 respondents (67%) felt an impact on their mental health and their ability to do things they enjoyed.
- People reported feeling depressed and suffering from anxiety. This depression and anxiety was triggered by the illness itself as well as the consequences of the illness, such as reduced ability to work and earn money or access benefits.

The problem of diagnosis

- Looking at national trends, there should be more than 3,000 Haringey residents diagnosed with Long COVID. But currently there are only around 900 and most appear to be in the West of the borough. This points to a real problem of undiagnosed Long COVID in the more deprived East of the borough.
- Some people experienced difficulty getting a diagnosis of Long COVID from their GP or clinician.
- Seven of the 15 respondents (47%) stated their GP / Clinician had little or no knowledge about Long COVID. GPs lack of knowledge about Long COVID was a recurring theme.
- Six of the 21 respondents (29%) had not sought medical care for their Long COVID symptoms. Reluctance or inability to seek help from the GP has been a general feature of the pandemic for many patients.

Recommendations

- Explore and address the issue of undiagnosed Long COVID amongst Haringey residents, particularly focusing on the more deprived East of the borough.
- More training for GPs so they are able to recognise Long COVID symptoms, provide a diagnosis, provide the patient with good quality information, and refer on appropriately.
- More training for GPs so they can support Long COVID patients appropriately within primary care by giving them information about self-management techniques, helplines, local support groups etc.
- Develop effective communications around Long COVID for the general public, raising awareness of what it is and encouraging them to seek medical advice and help.

Getting the right healthcare

People identified a need for better access to health services, both at primary care through GPs and at secondary care through Long COVID clinics.

- 13 of the 21 respondents (62%) had experienced difficulties in getting appropriate healthcare support.
- Self-management was found to be the single most helpful healthcare intervention. Self-management included diet, exercise (e.g. yoga), rest, fatigue management and pacing.
- Most people found out about self-management techniques themselves. Only two people received information about self-management techniques from a healthcare professional.

- 15 of the 21 respondents (71%) had to do their own research on Long COVID.
- Patients did their own research due to the lack of support from the NHS, including unsympathetic GPs, ineffective advice, long waits for diagnosis and long waits for the Long COVID clinic.
- There were very long waits for the Long COVID clinic or other services. In some cases people were waiting several months for a first appointment with the Long COVID clinic.
- Some patients were not confident the Long COVID clinic could help them with the right tests or treatment.
- People said they had to advocate for themselves and fight to access support from the NHS. Respondents were concerned that people from more deprived communities would not be able to fight for care in the same way and this was leading to inequity of service provision.

Recommendations

- Develop effective communications around Long COVID for patients, raising awareness of what it is, and encouraging people to seek medical advice and help.
- Develop effective patient information on Long COVID, and promote and distribute this to GPs. This should include information on self-management techniques, helplines, local support groups etc.
- Patients diagnosed with Long COVID should be given information and advice on appropriate self-management techniques and resources, regardless of the 12-week NICE guidance which identifies 'Post COVID syndrome' as starting no earlier than 12 weeks after infection.
- Develop Haringey based in-person and online peer support groups for people living with Long COVID.
- Develop a phone helpline to provide information and support on Long COVID, so people do not feel so isolated.
- Develop effective communications to promote the local support groups and services available for people living with Long COVID.
- Ensure at the point a patient is referred for Long COVID support the Long COVID pathway is explained to them in an accessible way.
- Ensure patients waiting for their first appointment with the Long COVID clinic at least get a phone call or an email providing good quality patient information on Long COVID e.g.. self-management techniques, helplines, local support groups, so they are able to access help and support whilst they are waiting.
- Ensure all patients on the Long COVID pathway are clear about how they will be followed-up after their first appointment.
- Ensure all patients on the Long COVID pathway understand how to contact the clinical team responsible for their care through phone and email.

- Ensure there is more consistency in people's experiences accessing the Long COVID pathway, taking into account patients' physical, mental and social needs.
- Continue to analyse and monitor Long COVID data for Haringey residents across localities and communities to help ensure Long COVID support and services are being accessed by all localities and communities in an equitable way.

4. Detailed findings

i) Impact of Long COVID on health and wellbeing

Long COVID has had a huge impact on people's physical and mental health and wellbeing and on their day-to-day lives.

Employment and finances

- 15 out of 21 respondents (71%) said Long COVID had impacted their ability to work or the number of hours they can work.
- Seven out of 21 respondents (33%) said there had been an impact on their job security.
- Two people were made redundant and one accepted voluntary severance (along with others in their firm who also had Long COVID.)
- Three people felt Long COVID was holding them back at work, and two reported the cognitive symptoms of Long COVID prevent them from doing their jobs well.
- Seven out of 21 respondents (33%) said their finances were affected.



I am so worried about keeping my job. I had to go back to work after 4 weeks off, because they would have taken away my salary otherwise and I'd be left only with statutory sick pay which I can't live on. It's so stressful and I am struggling to keep up with my job which is very cognitive.



I was already on Personal Independent Payment (PIP) and Employment and Support Allowance (ESA) (support group) for long-term disabilities, but I was starting to get to a point where I was looking for a very part-time job before I got COVID. It's completely floored me, and 10 months later I'm practically housebound.

Case Study

Laurence's story – School student's education impacted by Long COVID

“There's so much pressure on schools to pretend it isn't happening...He's had about 18 days off and it worries me that I get automatic letters saying he is persistently absent. The school is being reasonable... but getting a court letter must be absolutely terrifying for vulnerable parents.”

Laurence's mother

Laurence is a 14-year-old boy with Long COVID. He was 13 when he first tested positive for COVID-19. Laurence has had to take 18 days off school with Long COVID.

Laurence has been seen by a paediatric physiotherapist and has received painkillers but no treatment for persistent malaise and fatigue which are a big part of his Long COVID.

Laurence's mother said it was essential to make schools safer:

“It's a strange thing that we are just sending our kids out to get infected. Why aren't we using air purifiers and sorting out ventilation?”

Physical health

- 16 out of 21 (76%) respondents said their physical health had been impacted by Long COVID.
- They reported significant, wide ranging, multiple and severe physical health impacts. These included fatigue / exhaustion, stomach problems, heart palpitations, headaches, brain fog, aching limbs, insomnia, pain in muscles and bones, severe back pain, joint pain, decreased mobility, and loss of taste and smell.
- The physical health impacts have triggered severe and long-term impacts on their overall wellbeing and mental health.
- People expressed worry and frustration that they couldn't recover after such a long period of ill health.



Physically I am a shadow of myself – I have decreased mobility and joint pain. I have headaches and nausea. Mentally – it’s a yo-yo: anxiety is there all the time but I never know what else I’m going to feel e.g. anger / irritation / depression / gnawing anxiety / irritation / apathy / bouts of crying etc.



At the age of 35 I’m not able to live a normal life. I’m in so much pain and I’m so exhausted that all I can do is force myself to work from home and stay in bed. All the joy is gone, there is only pain, exhaustion, and anticipation of more pain. I used to be an active smart person, now due to the brain fog I feel like an idiot most of the time.

Mental Health

- 14 out of 21 respondents (67%) felt an impact on their mental health and their ability to do things they enjoyed.
- People reported feeling depressed and suffering from anxiety. This depression and anxiety was triggered by the illness itself as well as the consequences of the illness, such as reduced ability to work and earn money or access benefits.



I can’t exercise as my heart rate goes up and I get chest pain and feel so exhausted after a short amount of slow walking. I am so down a lot of the time, feel guilty for not working and sad about missing so many of my usual social activities. My relationship is suffering as I’m so down and not at all fun.



I am stuck in this nightmare can't make plans and don't know when it will end.

Day to day living

- Long COVID has had an impact on most peoples' ability to keep up with home chores / admin.

ii) The problem of diagnosis

- Looking at national trends, there should be more than 3,000 Haringey residents diagnosed with Long COVID, but currently there are only around 900 and most appear to be in the west of the borough. This points to a real problem of undiagnosed Long COVID in the more deprived east of the borough.
- 15 of the 21 respondents (71%) sought medical care for their Long COVID symptoms.
- 12 of the 15 respondents who went to their GP have been formally diagnosed with Long COVID.
- Some people experienced difficulty getting a diagnosis of Long COVID from their GP or clinician. Three patients were not satisfied with the service they received from their GP, feeling their GP did not diagnose or refer them correctly - one patient was given no diagnosis and two were given a different diagnosis.
- Seven out of 15 respondents (47%) stated their GP/Clinician had little or no knowledge about Long COVID and GP's lack of knowledge about the condition was a recurring theme.
- Six of the 21 respondents had not sought medical care for their Long COVID symptoms. Four said it was because they didn't think their GP could help, three didn't think their case was a priority, and one did not know they had Long COVID. Reluctance or inability to seek help from the GP has been a general feature of the pandemic for many patients.



I have been complaining of symptoms since early June when I was seen by a GP. and it's taken until I went to A&E in early September with concerns over my severe breathing difficulties for me to get a diagnosis.



One doctor told me I would not be able to get diagnosed with Long COVID without a blood test, despite there being no diagnostic test for long covid. He refused to believe the symptoms I described arrived after I contracted COVID, Another doctor at the practice referred me to the post COVID clinic immediately after a phone consultation, and the clinic confirmed a post-COVID diagnosis without requiring a blood test.

Case Study

Haima's story - Fighting for recognition from her GP

“The most stressful and frustrating part has been getting my GP surgery to take my Long COVID seriously and make referrals.”

Haima's GP had never heard of Long COVID, and she had to fight for a referral for further investigations. She felt her GP was “...dismissive, lacking in any management plan and keen to psychologise my symptoms”. After months of waiting for a first referral appointment Haima went to A&E with heart problems. The A&E doctor “labelled it anxiety”.

Haima was finally able to access care from the UCLH Long COVID clinic. She feels they validated her symptoms and suggested strategies and a management plan. Her symptoms are gradually improving, but she says the main reason for improvement is “time”.

iii) Getting the right healthcare

- Most respondents did not feel they received the right kind of care or timely care from the NHS.
- 13 of the 21 respondents (62%) had experienced difficulties in getting appropriate healthcare support.
- Self-management was found to be the single most helpful healthcare intervention. Self-management included diet, exercise (e.g. yoga), rest, fatigue management and pacing.
- Most people found out about self-management techniques themselves. Only two people received information about self-management techniques from a healthcare professional.
- 15 of the 21 respondents (71%) had to do their own research on Long COVID.
- Some patients sought information from Long COVID support groups.
- Patients did their own research due to the lack of support from the NHS, including unsympathetic GPs, ineffective advice, long waits for diagnosis and long waits for the Long COVID clinic.
- Five patients had to chase up appointments and referrals to get access to care.
- There were very long waits for the Long COVID clinic or other services. In some cases people were waiting several months for a first appointment with the Long COVID clinic.
- Some patients were not confident the Long COVID clinic could help them with the right tests or treatment.
- One person was not aware these services existed.
- People said they had to advocate for themselves and fight to access support from the NHS. One patient even had to contact their MP to ask for help.
- Respondents were concerned that people from more deprived communities would not be able to fight for care in the same way and this was leading to inequity of service provision.

Case Study

Ed's story – Turning to his local MP was the quickest way to get healthcare support

Ed's GP referred him for various tests and investigations, but these tests were inconclusive. Finding it impossible to get a clear diagnosis or appropriate treatment, Ed wrote to his MP Catherine West. West wrote to the Chief Executive of UCLH, and Ed was quickly offered a series of investigations by the hospital's Long COVID clinic which he found to be helpful.

Ed's Long COVID symptoms are gradually improving mainly due to pacing but his Long COVID is still significantly impacting his ability to work and carry out normal tasks in the day.

Ed feels a sense of guilt that he was able to advocate for himself and receive treatment whereas many other sufferers of Long COVID cannot do so. He was able to get himself on the waiting list for the Long COVID clinic by contacting his MP and he accessed the support that is available online. He worries that people who are less educated or from a more deprived or diverse background, may not be as well equipped to fight for the same treatment.

“You can't see equity in how the systems are set up. Those thresholds to get into the clinic are high and that concerns me from a societal point of view. It's miserable that people have to fight for something that is their right.”



I haven't tried any interventions, I didn't know a specialist clinic existed.



Doctors should have offered referral to post COVID clinic as soon as they knew I was suffering, not 18 months later after having to beg.



I had to wait a long time for a diagnosis, I don't know how much my GP knows about it but he referred me to the Long COVID clinic but I have not heard anything from them yet. I have read the NHS website. I feel rather alone with it.



Waiting for months still for an appointment at the Long COVID clinic, Still no news on that - I first saw my GP in July.



I had to wait 3 months to be referred by my GP to the Long COVID clinic and then another 2 months before a call / appointment. After the excitement of being finally seen by the 'experts' and a few tests being organised there was nothing for months...App (My Chart) does not work...Not shared with GP - why not? 10 months in and feel completely despondent with clinic in so many ways.

Case Study

Zofia's story – Refused support for her Long COVID symptoms

Zofia has suffered a continuing process of refusal of support for her Long COVID to such an extent that she reached out to Healthwatch asking us to help her get “tests and any kind of support.” Two referrals to hospital made by her GP were refused and one blood test appointment was cancelled.

We contacted her GP who agreed to review her case and copied in the UCLH Long COVID clinic. We have not received any communication from the Long COVID clinic to date, however Zofia was finally seen by the Long Covid clinic in October 2021.

Zofia's failure to improve, coupled with inadequate healthcare has resulted in mental health impacts, for which Zofia has been prescribed anti-depressants by her GP.



Complete lack of advice and support on how to manage my symptoms. I've been told to rest, to drink lots of water and eat well. This is advice you'd give anyone and isn't at all helpful. I haven't got a clue what to do – should I try to exercise more? What else? How to manage breathing? Is chest pain a concern?



I've received zero support from the doctors. I have been left to suffer on my own.



There has been minimal support from the Long COVID clinic. I have therefore had to do my own research into Long COVID / what can help as I want to recover!



When I developed persistent symptoms the long-term impacts of covid were unknown – after summer 2020 I joined ‘long covid support’ on Facebook where the scale became clear and treatments for Long COVID were discussed.

iv) How could things be improved?

- People identified a need for better access to health services, both at primary care through GPs and at secondary care through Long COVID clinics.
- Respondents wanted to see GPs better trained and more knowledgeable about Long COVID and treatments for the condition.
- Shorter waiting times were a priority.
- A telephone helpline was suggested for patients to help overcome the isolation.
- In-person locally based Long COVID support groups were suggested so those unable to access online support could be helped.
- Better communication and publicity were seen as useful, promoting the support that is available for people living with Long COVID, so people come forward.
- Respondents talked about the inequality of access to Long COVID health services, especially for those from diverse backgrounds or from disadvantaged communities. They may not be getting the support and care they need because they are less able to advocate for themselves.



We need Long COVID support groups so you can share stories with other people, as many people around you don't believe your symptoms.

5. Recommendations

1. Statutory services (Haringey Council, NCL CCG, and NHS Trusts) should model being a good employer for people living with Long COVID. Their HR departments should ensure reasonable adjustments are made, and flexible working arrangements are explored, to ensure people can keep their jobs and continue to work.
2. Information, help and support should be provided to people living with Long COVID to ensure they are able to access any benefits they are entitled to.
3. Haringey Local Education Authority should work pro-actively with schools, colleges, headteachers and teachers to support families whose child/young person is absent from school/college due to Long COVID.
4. Explore and address the issue of undiagnosed Long COVID amongst Haringey residents, particularly focusing on the more deprived East of the borough.
5. More training for GPs so they are able to recognise Long COVID symptoms, provide a diagnosis, provide the patient with good quality information, and refer on appropriately.
6. More training for GPs so they can support Long COVID patients appropriately within primary care by giving them information about self-management techniques, helplines, local support groups etc.
7. Develop effective communications around Long COVID for the general public, raising awareness of what it is and encouraging them to seek medical advice and help.
8. Develop effective patient information on Long COVID, and promote and distribute this to GPs. This should include information on self-management techniques, helplines, local support groups etc.
9. Patients diagnosed with Long COVID should be given information and advice on appropriate self-management techniques and resources, regardless of the 12-week NICE guidance which identifies 'Post COVID syndrome' as starting no earlier than 12 weeks after infection.

10. Develop Haringey based in-person and online peer support groups for people living with Long COVID.
11. Develop a phone helpline to provide information and support on Long COVID, so people do not feel so isolated.
12. Develop effective communications to promote the local support groups and services available for people living with Long COVID.
13. Ensure at the point a patient is referred for Long COVID support the pathway is explained to them in an accessible way.
14. Ensure patients waiting for their first appointment with the Long COVID clinic receive a phone call or an email providing good quality patient information on Long COVID e.g. self-management techniques, helplines, local support groups, so they are able to access help and support whilst they are waiting.
15. Ensure all patients on the Long COVID pathway are clear about how things will be followed-up after their first appointment.
16. Ensure all patients on the Long COVID pathway understand how to contact the clinical team responsible for their care through phone and email.
17. Ensure there is more consistency in people's experiences accessing the Long COVID pathway, taking into account patients' physical, mental and social needs.
18. Continue to analyse and monitor Long COVID data for Haringey residents across localities and communities to help ensure Long COVID support and services are being accessed by all localities and communities in an equitable way.

Appendices

Appendix A:

Patient Profiles

- 15 of the 21 respondents had tested positive for COVID-19 prior to experiencing Long COVID symptoms. Six had not been tested.
- 15 have been living with Long COVID for more than nine months and six of these have been living with Long COVID for more than a year.
- Only one person said they had recovered.
- 19 of the 21 respondents had received at least one vaccine dose. The survey did not ask if they were vaccinated before or after contracting Long COVID.
- 15 patients had seen their GP or other healthcare professional about their Long COVID.

Appendix B:

Long COVID – Background and Context

The precise causes of Long COVID are yet unknown and the recovery time varies for each patient. Currently in the UK there are two million people (3.1% of the population) living in private households with Long COVID in the UK (selfreported) and 826,000 who have had Long COVID for more than 12 months.

https://bit.ly/ONS_Prevalence_LongCOVID_June22

More research is required to develop a standardised treatment pathway from diagnosis and treatment to 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' refers to when symptoms continue after four weeks of contracting COVID-19 and are not explained by an alternative diagnosis, and 'Post-COVID-19 syndrome' occurs if symptoms continue beyond 12 weeks. Both are commonly called Long COVID.

Long COVID presents itself through a wide range of clustered symptoms. A study conducted by University College London identified Long COVID patients self-reported over 200 symptoms across 10 organ systems.

https://bit.ly/UCL_LongCOVID_Symptoms_July21

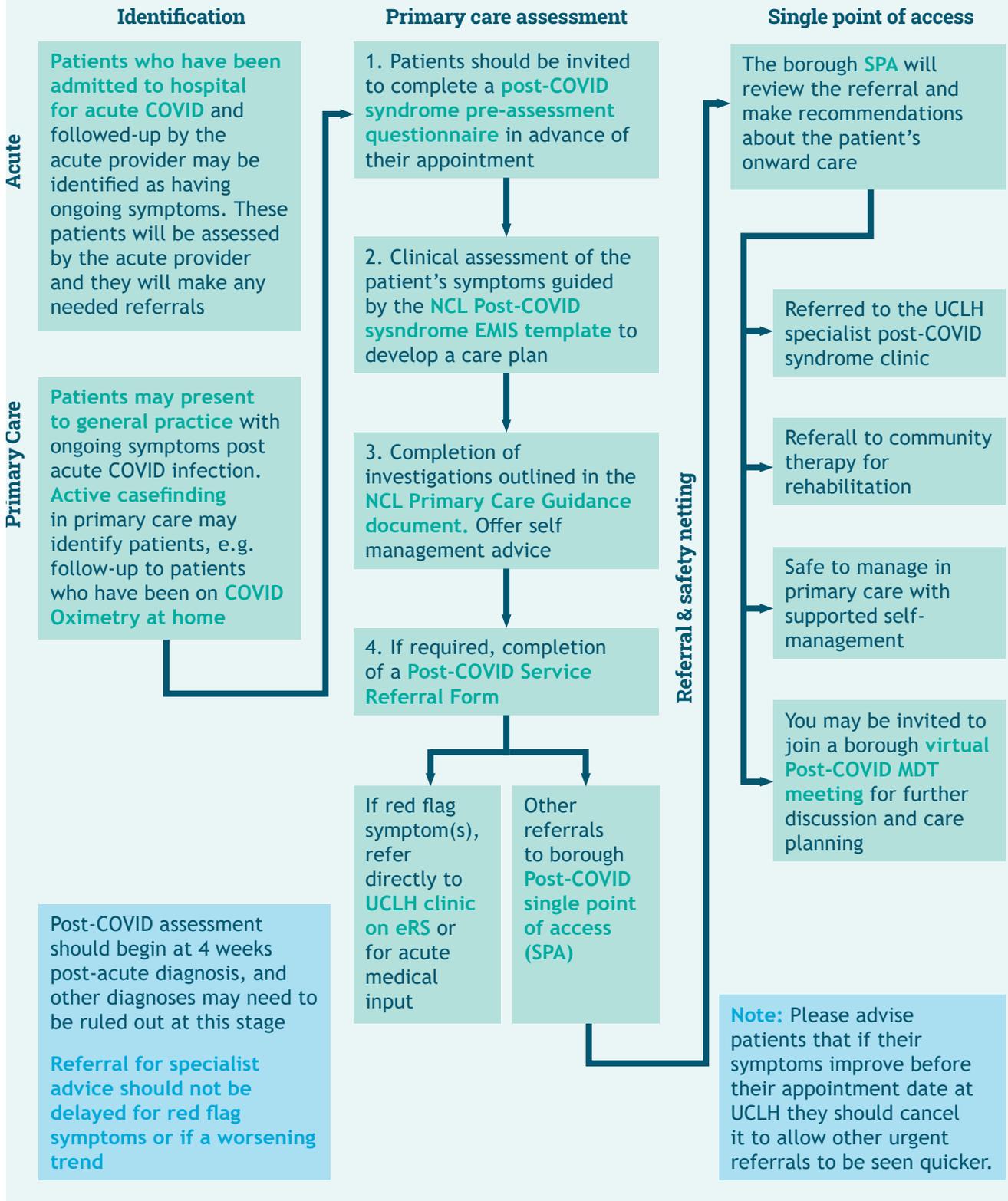
To tackle the debilitating impact of the condition, the Long COVID NHS Plan for 2021/22 outlined an investment of £100 million to support patients. There are now approximately 90 Post-COVID Specialist Clinics across England that support patients where previous medical care did not aid their recovery.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

North Central London Integrated Post-COVID Syndrome Service

NCL Patient Pathway



https://bit.ly/NCL_Healthwatch_LongCOVID_Report_2022
April 2022

Appendix C:

Monetary Policy Committee data on Long COVID and long-term sickness in the workforce

Bank of England Monetary Policy Committee (MPC) member, Michael Saunders, acknowledged that Long COVID is playing a role in the significant increase in people who are economically inactive due to long-term sickness.

Long COVID particularly affects women, and people of working age, and this is borne out in the MPC data.

Longer NHS waiting lists are also acknowledged by the MPC as a factor in the spike in long-term sickness.

https://bit.ly/MPC_Speech_Resolution_Foundation_May22

Extract from MPC speech to Resolution Foundation, 9 May 2022:

“However, since Q4-19, the economy’s potential output has fallen well below its previous trend. The workforce has shrunk by 440,000 people (1.3%) since Q4-19, and is 2.5% below the January 2020 forecast (see figure 5). The scale and persistence of this drop in labour supply has been a surprise to many forecasters, including us.

The interplay between Brexit and the pandemic has reduced net inward migration (and hence population growth), while participation has fallen markedly (especially among people aged 50-64 years).

Since Q4-19, the number of people aged 16-64 years that are outside the workforce and do not want a job has risen by 525,000 (1.3% of the 16-64 age population). This largely reflects increases in long-term sickness (roughly 320,000 people) and retirement (90,000), with smaller contributions from lower participation among students (65-70,000) and short-term sickness (30-35,000 people).

The share of the 16-64 population who are outside the workforce and do not want a job because of long-term sickness is a record high, with an especially sharp

rise among women (see figure 6). I suspect much of this rise in inactivity due to long-term sickness reflects side effects of the pandemic, for example Long COVID and the rise in NHS waiting lists.”

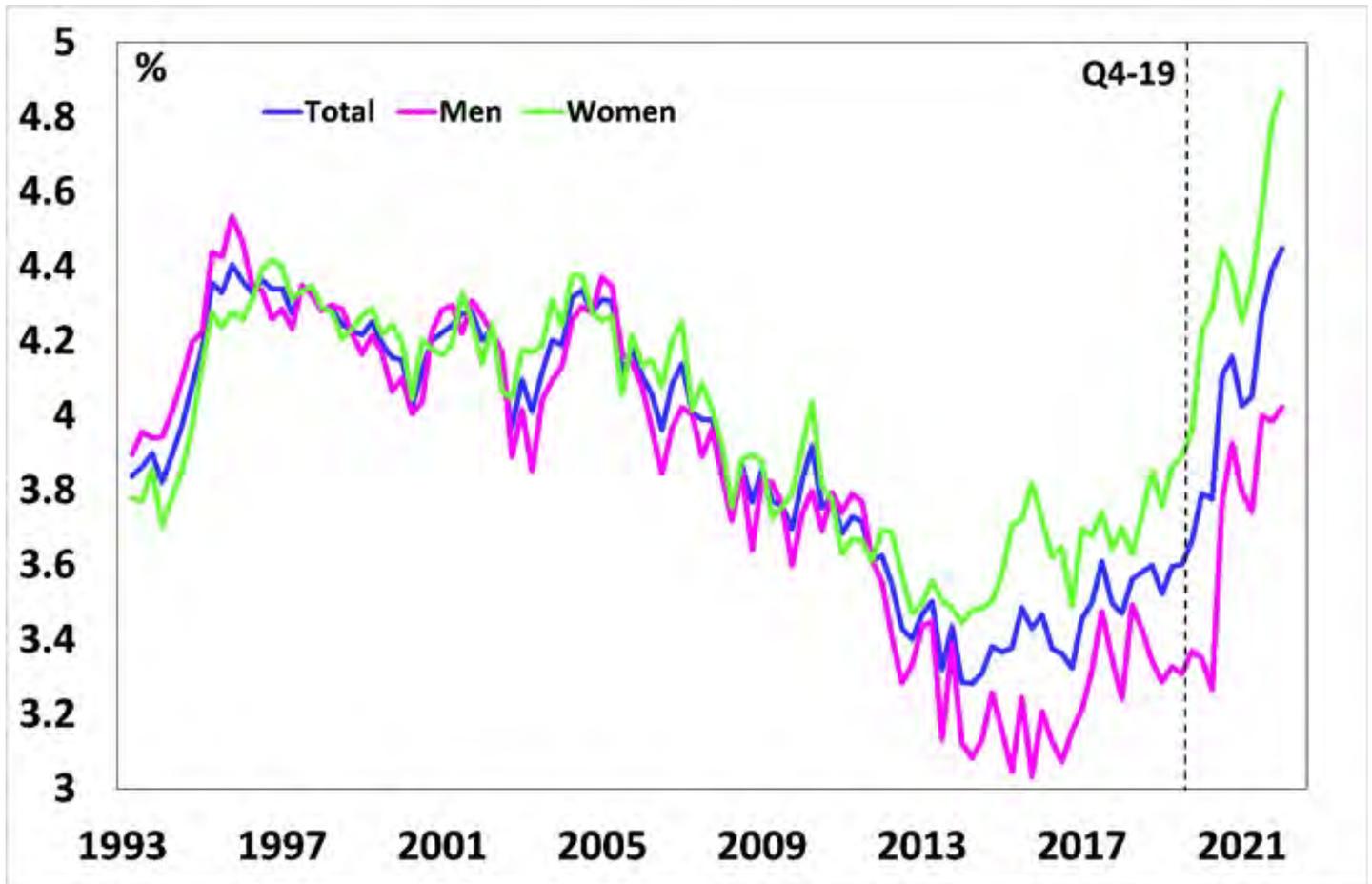


Figure 6. UK – Per cent of Adult Population Aged 16-64 Who Are Outside the Workforce and Do Not Want a Job Because of Long-term Sickness.



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020 8888 0579



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