Post-Covid Syndrome (PCS) in North Central London (NCL)

Needs Assessment v3.0 - June 2022

Camden and Islington Public Health team

Version History

Date	Version	Author	Changes
Aug-2021	V1.0	OH, AT, WJ	Created slide deck
Sep-2021	V1.1	AT, OH	Updated PCS estimates for NCL (charts/comments) as per latest ONS release
Nov-2021	V2.0	AT, WJ, OH	Updated PCS estimates for NCL (charts/comments) as per latest ONS release Added analysis of Specialist Clinic data (UCLH) Update background: updated ONS estimates and added impact of vaccination slides
May-2022	V3.0	AT, WJ, GB	Updated PCS estimates for NCL (charts/comments) as per latest ONS release Updated recorded prevalence of PCS and GP referrals to PCS clinics Updated analysis of Specialist Clinic data (UCLH) Updated background literature and added summary of NCL Healthwatch report

Acknowledgements

Project Lead

Wikum Jayatunga – Public Health Consultant, Camden and Islington Public Health

Quantitative analysis

Anjil Thapaliya – Intelligence and Information Officer, Camden and Islington Public Health

Literature and evidence

Olivia Hobden – Assistant Strategist, Camden and Islington Public Health

Gayathri Balasubramaniam – Assistant Strategist, Camden and Islington Public Health

CSU data extraction/EMIS searches support

Uche Osuagwu – Data Manager, Camden and Islington Public Health

Kadell Symmons – Project Support Officer (Enfield)

Aim

The aim of this slide pack is to summarise the available evidence and intelligence to understand the population health needs of Post Covid-19 Syndrome (PCS) in North Central London (NCL), to inform immediate service planning and the system response.

Context:

- The research and evidence base around Long COVID is **highly active and constantly evolving**.
- PCS needs will depend on the **future course of the pandemic** in the UK (such as the impact of the future waves of the pandemic, the emergence of variants, and the vaccination programme).
- This analysis should therefore be viewed a **snapshot of the current needs and evidence base**.
- Covid-19 has had a wide impact across numerous aspects of physical and mental health and wellbeing, of which PCS is only one element. These broader impacts are not within scope.

Methodology and data sources

Indicators	Definition	Source/Time period
Estimated prevalence of PCS, based on Office for National Statistics (ONS) Infection Survey	ONS UK estimated percentage of people with self-reported PCS* ONS population estimates mid-2019	ONS Infection Survey Data as of April 2022; ONS population estimates mid-2019
Recorded prevalence of PCS	Numerator: Total number of GP Registered people with recorded PCS as of 31st January 2022 Denominator: Overall GP registered population as of January 2022	Commissioning support units (CSU) dataset as of 31st January 2022
GP referrals to PCS clinics	Numerator: Total number of GP registered people given onward referrals related to Long COVID as of 31st January 2022 Denominator: Overall GP registered population as of January 2022	CSU dataset as of 31st January 2022

- Note: UK estimates include people living in private households and do not include those in communal establishments such as halls of residence prisons schools, hospitals, or care homes.

Contents

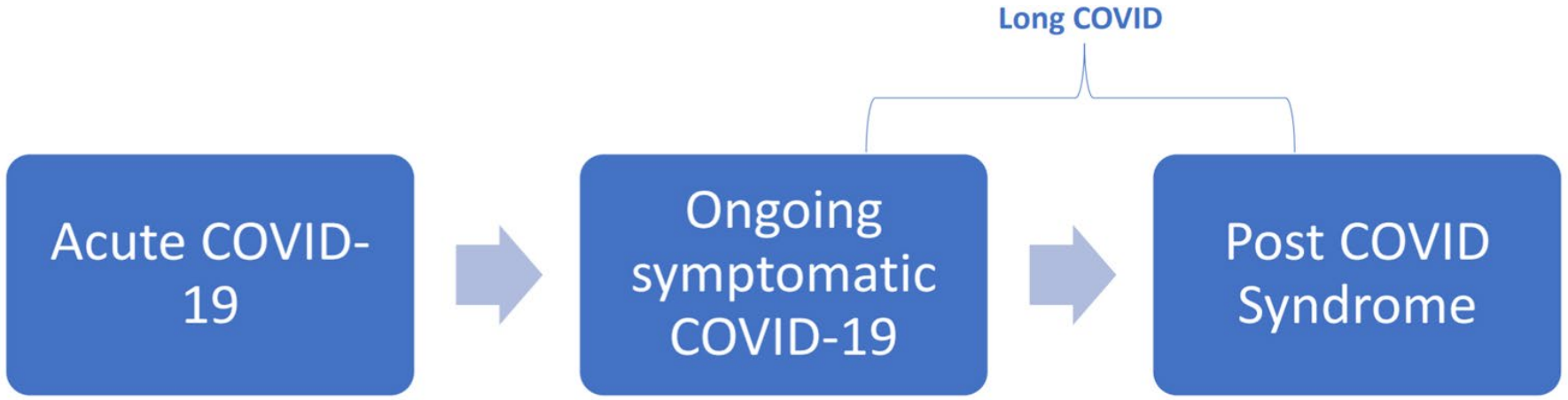
* Analysis for **Barnet** is currently unavailable

1. Background and Literature

- Post-Covid Syndrome (PCS) is a term used to describe the signs and symptoms caused by Covid-19 infection that persist beyond 12 weeks.
- A very wide range of symptoms and syndromes have been reported with PCS, and the pathology and biological mechanisms underlying these are poorly understood.
- Patients require a wide range of services and support, with a proportion experiencing significant impacts on their health, daily life and functioning.

Diagnostic Classification

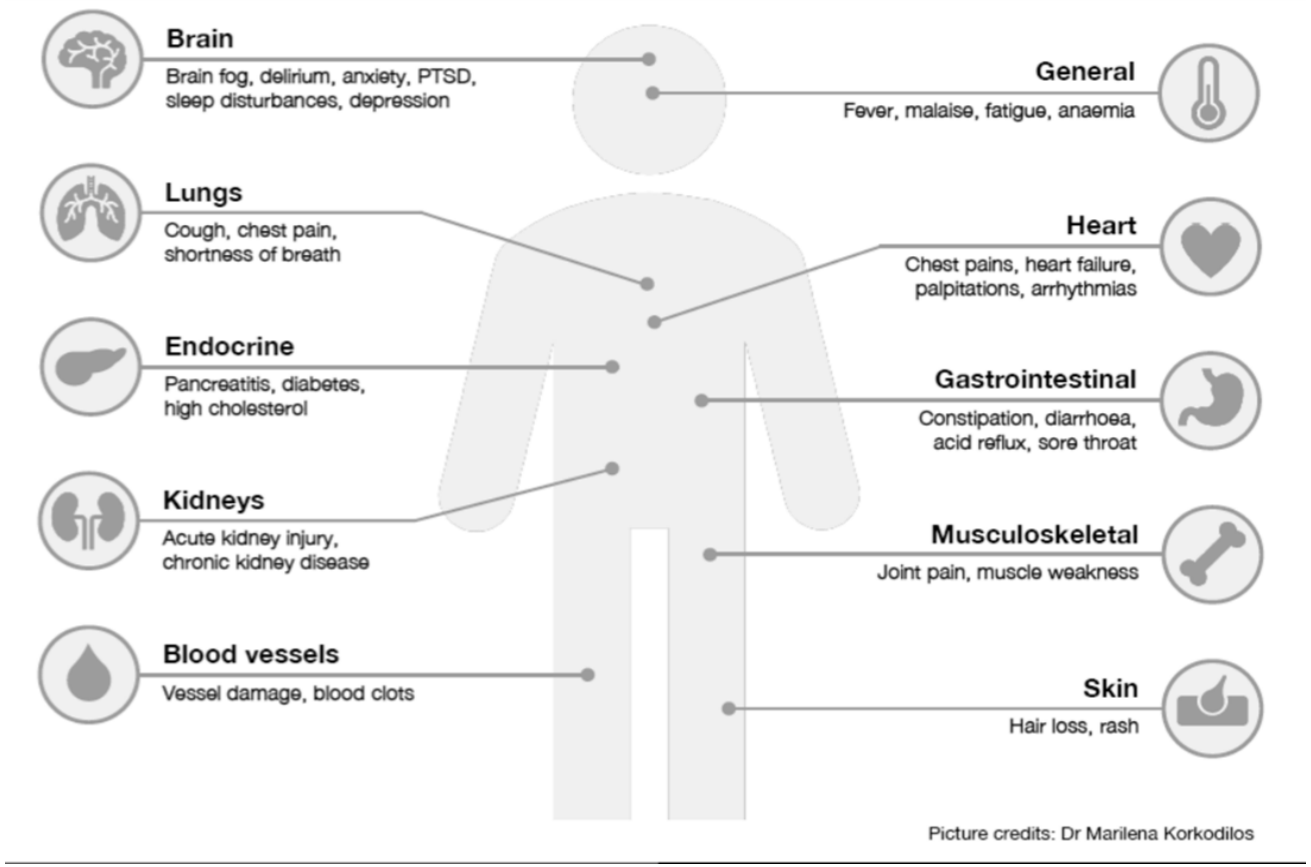
NICE Guidance (NG188) describes the following clinical definitions for the initial and ongoing illness from Covid-19.



[Long Covid] may be considered before 12 weeks while the possibility of an alternative underlying disease is also being assessed".

NICE guidelines [NG188]: COVID-19 rapid guideline: managing the long-term effects of COVID-19 was published on 18th December 2020

Symptoms



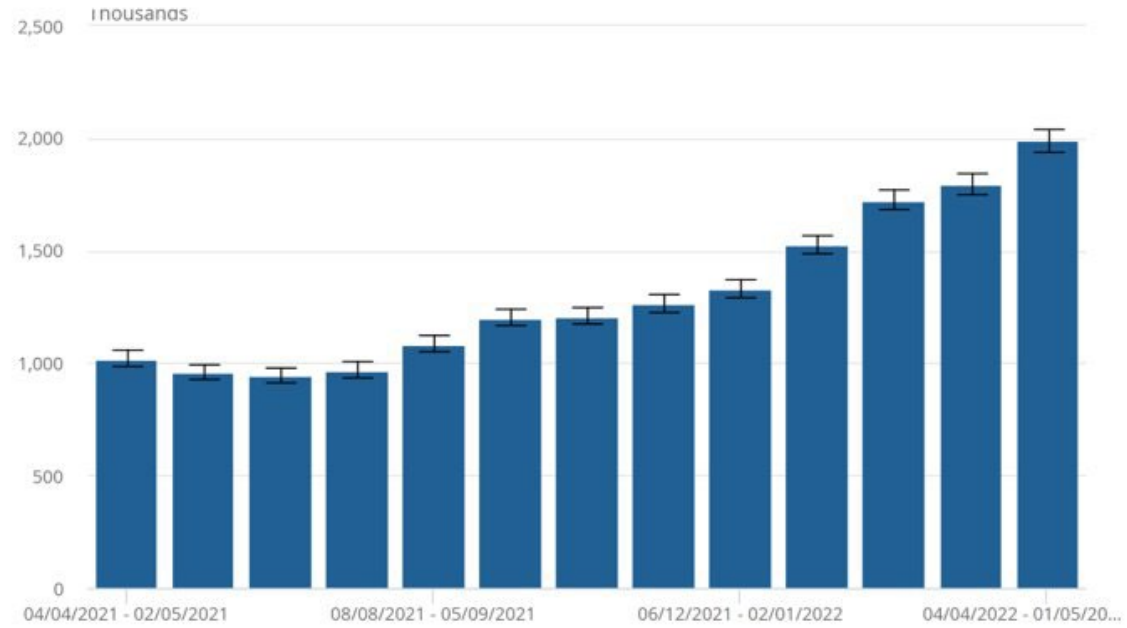
- Patients who experience Long COVID have reported **> 200 symptoms** which come and go over time.
- The most commonly reported post covid symptoms are fatigue, dyspnoea, cough, sleep disturbances, anxiety and depression, cognitive impairment, and difficulty concentrating.
- Taquet et al. 2021 estimated the incidence of 14 neurological and psychiatric outcomes 6 months after a confirmed diagnosis of COVID-19 to be nearly 34% of which 13% was a first diagnosis.
- NICE COVID-19 rapid evidence review

Prevalence

- An estimated 2.0 million people living in private households in the UK (3.1% of the population) were experiencing self-reported Long COVID, as of 1 May 2022 (ONS).
- Self-reported Long COVID has steadily increased, particularly following the new wave of infections resulting from the Omicron variant after December and January 2022 (see Figure 1).
- Of those self-reporting Long COVID, 42% first had (or suspected they had) COVID-19 at least 1 year previously, and 19% at least 2 years previously.

Figure 1

Estimated number of people living in private households with self-reported long COVID of any duration, UK: four-week periods ending 2 May 2021 to 1 May 2022



References:

- ONS Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK: 1 June 2022

Risk factors

What are the factors that influence severity of PCS?

As a proportion of the UK population, prevalence of self-reported Long COVID was greatest in people aged 35 to 49 years, females, people living in more deprived areas, those working in social care, teaching and education or health care, and those with another activity-limiting health condition or disability.

According to the latest ONS data (March 2022)

- **Sex**: Females reported 1.3 times as much Long COVID than males.
- **Age:** Adults aged 35 to 49 years and 50 to 69 years report Long COVID two times more than those aged at least 70 years. Self-reported Long COVID was lowest in children aged 2 to 16 years than in all adult age groups.
- **No of Symptoms:** Individuals who reported more than five symptoms in the first week (the median number reported) were significantly more likely to go on to experience Long COVID lasting longer than 28 days. This strong risk factor was predictive in both sexes and in all age groups. (Sudre et al, 2021)
- **Hospitalization and non-hospitalization** : Hospitalized and non-hospitalized adults were found with prolonged symptoms and limitations after COVID-19 (Tacquet et al, 2021)

References:

- ONS Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK: 5 April 2022
- Sudre, C. H., Murray, B., Varsavsky, T., Graham, M. S., Penfold, R. S., Bowyer, R. C., ... & Steves, C. J. (2021). Attributes and predictors of long COVID. Nature Medicine, 27(4), 626-631. https://www.nature.com/articles/s41591-021-01292-y
- Taquet M, Dercon Q, Luciano S, Geddes JR, Husain M, Harrison PJ (2021) Incidence, cooccurrence, and evolution of long-COVID features: A 6-month retrospective cohort study of 273,618 survivors of COVID-19. PLoS Med 18(9): e1003773. https://doi.org/10.1371/journal. pmed.1003773

Risk factors

- **BMI:** A higher BMI has been associated with myalgia and fatigue. (Sykes, D et al., 2021)
- **Pre-existing Health Conditions**: People with a health condition (excluding any Long COVID symptoms) that did not limit their day-to-day activities were 1.6 times more likely to report Long COVID than those without a health condition. Disabled people whose day-to-day activities were limited a lot or a little were 3.6 and 2.5 times more likely to report Long COVID, respectively, than those without a disability or health condition. (ONS) Additionally, it has been found that Asthma is significantly associated with Long COVID. (Sudre. C., 2021)
- **Other:** People with severe pneumonia, in whom higher heart rate and more lung abnormalities on admission to hospital Long COVID was more likely. (Moreno-Perez et al., 2020)
- **Ethnicity:** Though minority ethnic groups have been associated with increased risk of infection, this has not necessarily translated to increased risk of severe infection or death. A study at the Royal Free Hospital which followed up individuals testing positive for Covid, there was no difference between ethnic groups in terms of burden of physical or mental health symptoms, breathlessness score and ability to return to work between ethnicities. (Naidu et al., 2021)

References:

- Sykes, D. L., Holdsworth, L., Jawad, N., Gunasekera, P., Morice, A. H., & Crooks, M. G. (2021). Post-COVID-19 symptom burden: what is Long-COVID and how should we manage it?. Lung, 199(2), 113-119. https://link.springer.com/article/10.1007/s00408-021-00423-z
- ONS Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK: 5 August 2021
- Sudre, C. H., Murray, B., Varsavsky, T., Graham, M. S., Penfold, R. S., Bowyer, R. C., ... & Steves, C. J. (2021). Attributes and predictors of long COVID. Nature Medicine, 27(4), 626-631. https://www.nature.com/articles/s41591-021-01292-y
- Moreno-Pérez, O., Andres, M., Leon-Ramirez, J. M., Sánchez-Payá, J., Rodríguez, J. C., Sánchez, R., ... & Merino, E. (2020). Experience with tocilizumab in severe COVID-19 pneumonia after 80 days of follow-up: A retrospective cohort study. Journal of autoimmunity, 114, 102523.
- Naidu et al. (2021) The impact of ethnicity on the long-term sequelae of COVID-19: follow-up from the first and second waves in North London

Impact of PCS in Children

- Although COVID-19 is unlikely to cause severe disease in children, estimates of the prevalence of Long COVID symptoms based on the ONS Infection Survey suggest that 13% of children aged 2–10 years and 15% of those aged 12–16 years have at least one persistent symptom 5 weeks after testing positive. (Gurdasani et al., 2021)

- Although COVID-19 in children is usually of short duration with low symptom burden, some children with COVID-19 experience prolonged illness duration. Reassuringly, symptom burden in these children did not increase with time, and most recovered by day 56 (Molenti et al., 2021). However, a small proportion develop MIS-C (a Kawasaki-like hyper-inflammation) (Buonsenso, 2021).

References:

- Buonsenso, D, (2021)., Preliminary Evidence on Long COVID in children. https://www.medrxiv.org/content/10.1101/2021.01.23.21250375v1.full
- Gurdasani, D., Alwan, N. A., Greenhalgh, T., Hyde, Z., Johnson, L., McKee, M., ... & Ziauddeen, H. (2021). School reopening without robust COVID-19 mitigation risks accelerating the pandemic. The Lancet, 397(10280), 1177-1178. https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(21)00622-X/fulltext
- Molteni, E., Sudre, C. H., Canas, L. S., Bhopal, S. S., Hughes, R. C., Antonelli, M., ... & Duncan, E. L. (2021). Illness duration and symptom profile in symptomatic UK school-aged children tested for SARS-CoV-2. The Lancet Child & Adolescent Health. https://www.thelancet.com/journals/lanchi/article/PIIS2352-4642(21)00198-X/fulltext

Management of PCS

- **NICE** have developed clinical guidelines [NG188] on the management of Long COVID, based on the principles of:
  - Holistic person-centred assessment
  - Self-management and supported self-management
  - Multidisciplinary rehabilitation
  - Follow up and monitoring appropriate to need

- **Post-Covid clinics:** There are currently around 80 post covid clinics in England that take referrals from primary care for adults or children who are experiencing a range of symptoms that might include brain fog, anxiety, depression, breathlessness, and fatigue. A range of other medical specialties may need to be involved, depending on each patient's symptoms, such as cardiology and neurology.

References:

- Barker-Davies, R. M., O'Sullivan, O., Senaratne, K. P. P., Baker, P., Cranley, M., Dharm-Datta, S., ... & Bahadur, S. (2020). The Stanford Hall consensus statement for post-COVID-19 rehabilitation. British journal of sports medicine, 54(16), 949-959. https://bjsm.bmj.com/content/54/16/949
- National Institute for Health Research,. (2021) Living with Covid19 – Second review. doi: 10.3310/themedreview_45225

- **Psychological Care:** It is well established that long term physical health conditions can trigger psychological problems such as depression and anxiety. Unexplained and long-lasting symptoms in Long COVID give rise to a sense of isolation. In England, low-intensity interventions from trained practitioners have been offered to people with long-term conditions through the Improving Access to Psychological Therapies (IAPT) programme. It has been reported that 50% of people receiving IAPT recover and two-thirds show significant improvement. The service accepts both self-referrals and referrals from health professionals. (NIHR)

- **Self-Management Strategies**: Self-management practices among individuals with Long COVID are not widely researched or published. A scoping review by Brown et al. (2022) found that patients and patient advocacy groups have reported an absence of timely support and poor recognition of Long COVID. This has been reasoned by insufficient knowledge and evidence of Long COVID as well as over pressured health-care systems. Lack of support has led to loss of faith in health-care service delivery, causing individuals with Long COVID to sources other sources of treatment or support, including under studied remedies/supplements to manage symptoms. People are turning to social media platforms where individuals can share their self-management experiences. While these platforms can be a helpful source of support, they can also a source of unverified information.

References:

- National Institute for Health Research,. (2021) Living with Covid19 – Second review. doi: 10.3310/themedreview_45225
- van Hooft, S.M., Been-Dahmen, J.M., Ista, E., van Staa, A. and Boeije, H.R., 2017. A realist review: What do nurse-led self-management interventions achieve for outpatients with a chronic condition? Journal of Advanced Nursing, 73(6), pp.1255-1271.

Impact of vaccination

In a UKHSA review of 15 studies looking at the impact of vaccination on Long COVID:

- 6 of 8 studies assessing the effectiveness of vaccination before COVID-19 infection suggested that vaccinated cases (1 or 2 doses) were less likely to develop symptoms of Long COVID following infection.
- Some studies looked at the impact of vaccination on people with established Long COVID. A high proportion (up to 70%) reported no change in symptoms. More people reported an improvement in symptoms though a small minority reported a worsening.
- All studies were observational, so the results may be from differences other than vaccination, and there was large heterogeneity between studies in the definition of Long COVID.

References :

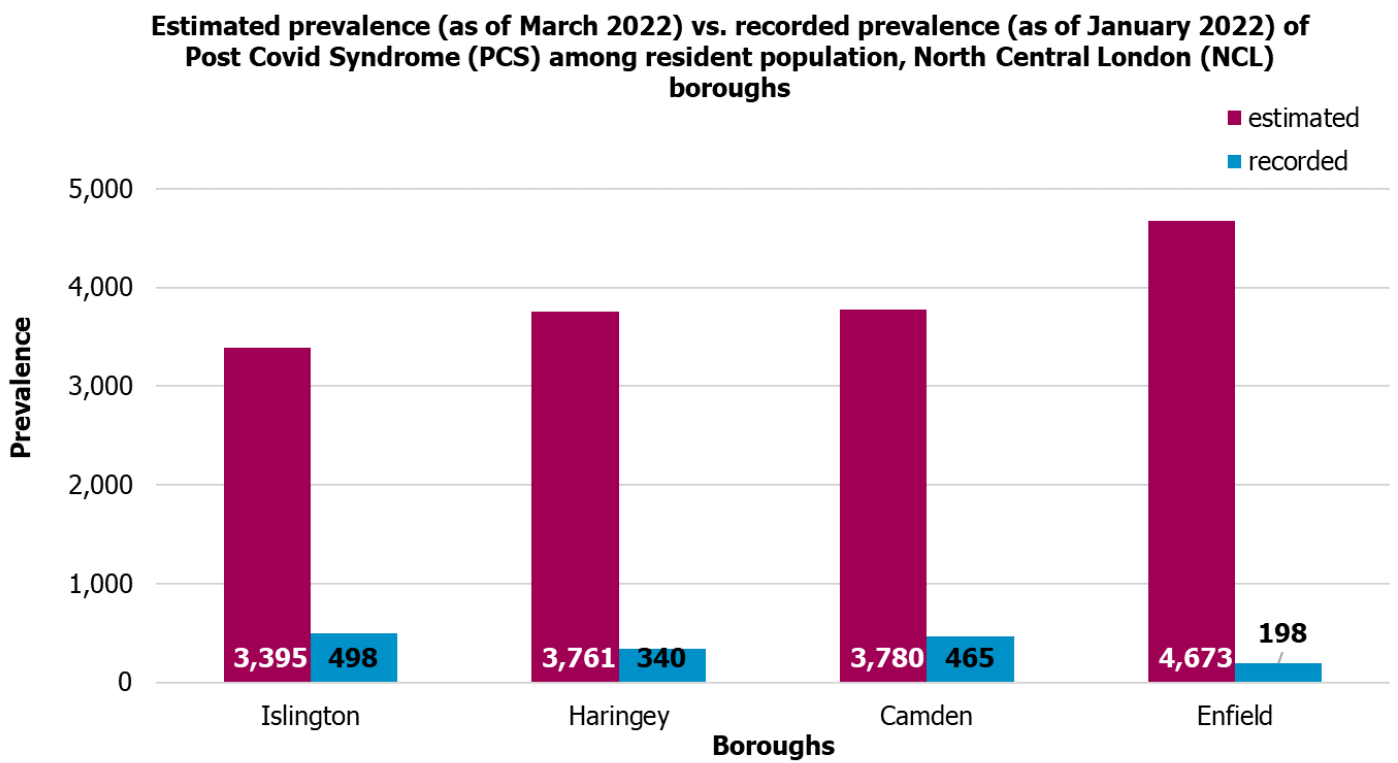
- UK Health Security Agency. SARS-CoV-2 variants of concern and variants under investigation in England: Technical briefing 34. 2022. Available from: https://ukhsa.koha-ptfs.co.uk/cgi-bin/koha/opac-retrieve-file.pl?id=fe4f10cd3cd509fe045ad4f72ae0dfff

2. Post-Covid epidemiology in NCL

This section presents an overview of the estimated prevalence of Post-Covid syndrome (PCS) in NCL boroughs, modelled based on the COVID-19 Infection Survey Data.

Data source: Office for National Statistics (ONS) COVID-19 Infection Survey Data, April 2022; ONS population estimates,mid-2019; GLA 2016 based ethnic group projections; English Indices of Deprivation, 2019

NCL estimated vs. recorded prevalence, by borough

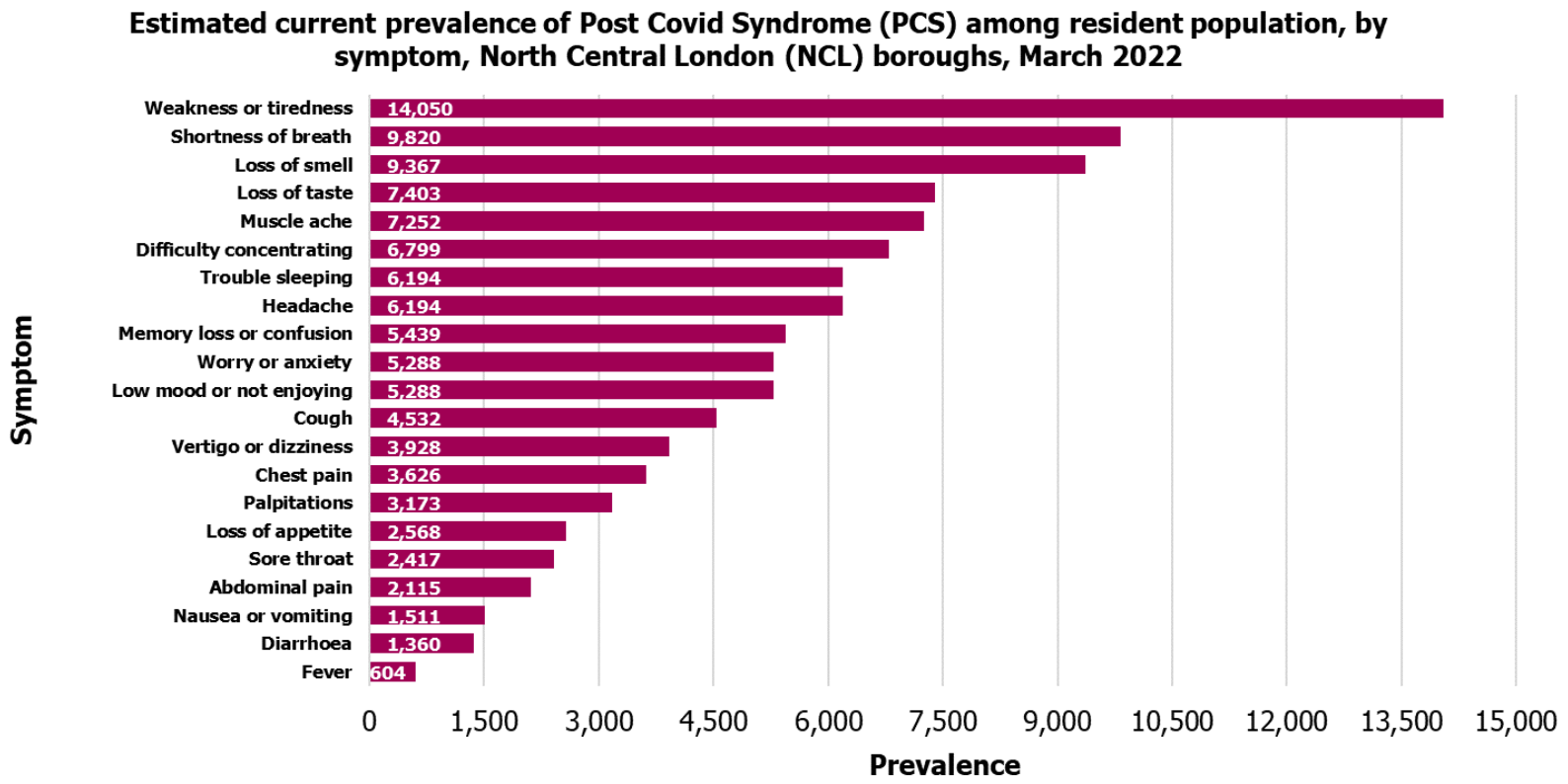


Note: Modelling of current prevalence is based on Office for National Statistics (ONS) Infection Survey data; Data for Barnet is not available, hence excluded from this analysis

Source: ONS population estimates, mid-2019; ONS COVID-19 Infection Survey data, April 2022; Commissioning support units (CSU) dataset, January 2022

- According to the ONS Infection survey data, the estimated prevalence of PCS among the population is **1.4% in the London Region** as of March 2022.
- **Estimated prevalence** of PCS in NCL boroughs **is far higher than observed prevalence** from recorded diagnoses.
- **Note**: The regional estimate has been applied to the local population estimates in the NCL boroughs to derive local PCS estimates by borough. **NHSE estimate that 20% of Long COVID cases require post covid pathway care**.

NCL estimated prevalence, by symptom



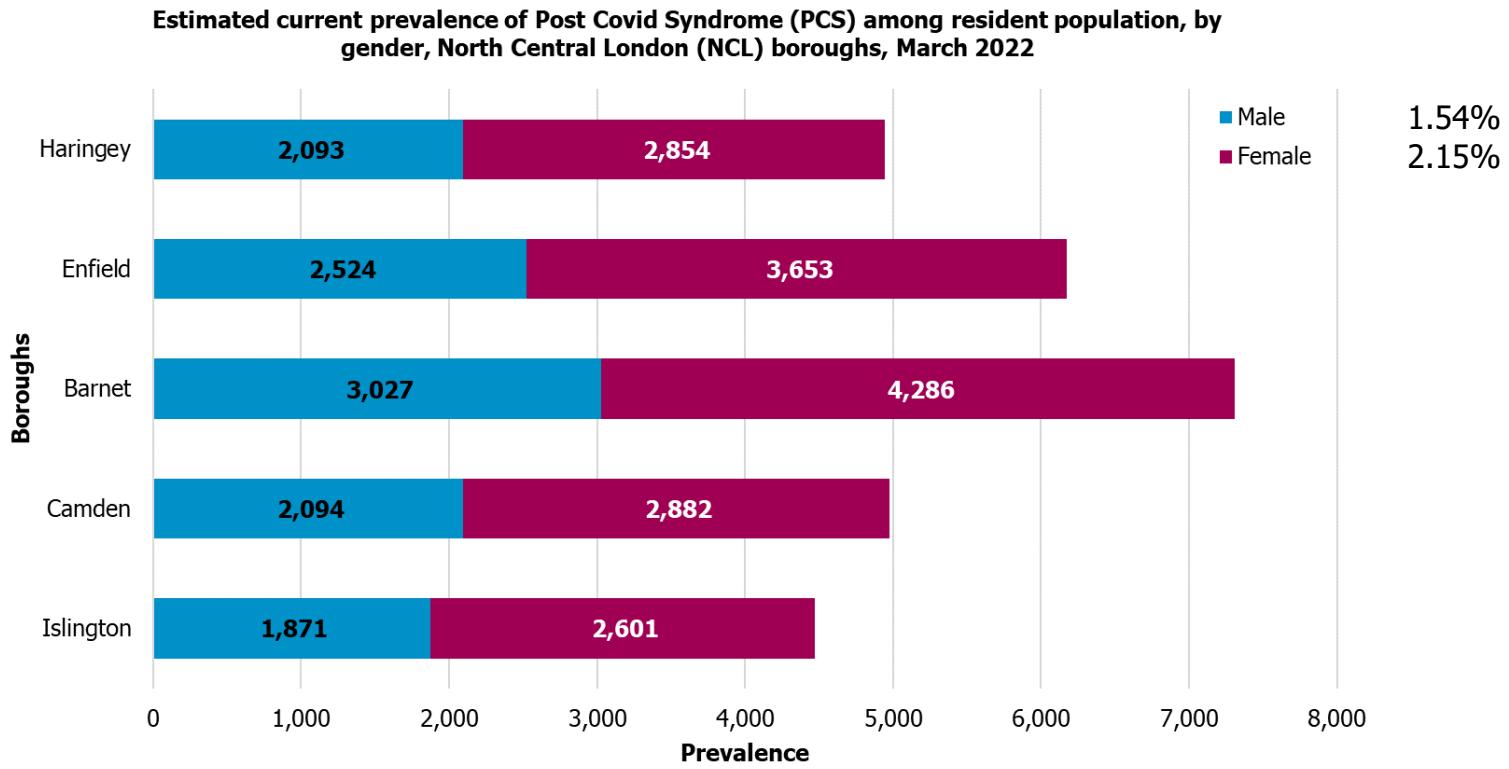
Note: Modelling of current prevalence is based on Office for National Statistics (ONS) Infection Survey data

Source: ONS population estimates, mid-2019; ONS COVID-19 Infection Survey data, April 2022

- According to the ONS Infection survey data, **weakness/tiredness** was the most common symptom reported among the general population with self-reported Long COVID (duration at least 12 weeks) followed by shortness of breath, loss of smell, loss of taste and muscle ache (UK, March 2022).

- **Note**: The UK estimate has been applied to the total of local NCL population estimates to derive the PCS estimates by symptom in the NCL area.

NCL estimated prevalence, by gender

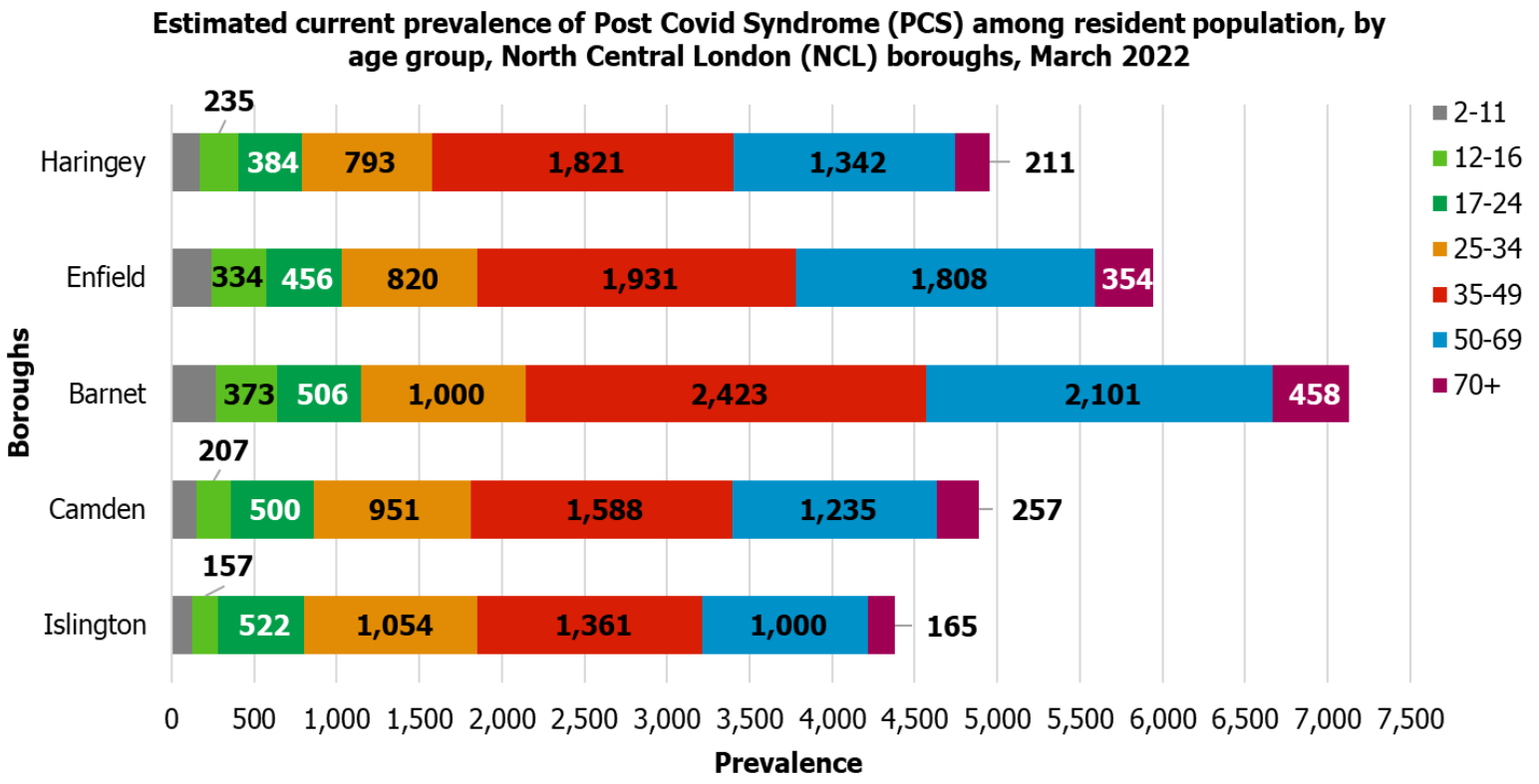


- PCS prevalence is estimated to be **higher in women than men.**
- According to the ONS Infection survey data, the estimated prevalence of PCS is **1.54% among males** and **2.15% in females** (UK, March 2022).
- **Note**: The UK estimates by gender have been applied to the local population estimates in the NCL boroughs to derive local estimates of PCS by gender.

Note: Modelling of current prevalence is based on Office for National Statistics (ONS) Infection Survey data

Source: ONS population estimates, mid-2019; ONS COVID-19 Infection Survey data, April 2022

NCL estimated prevalence, by age

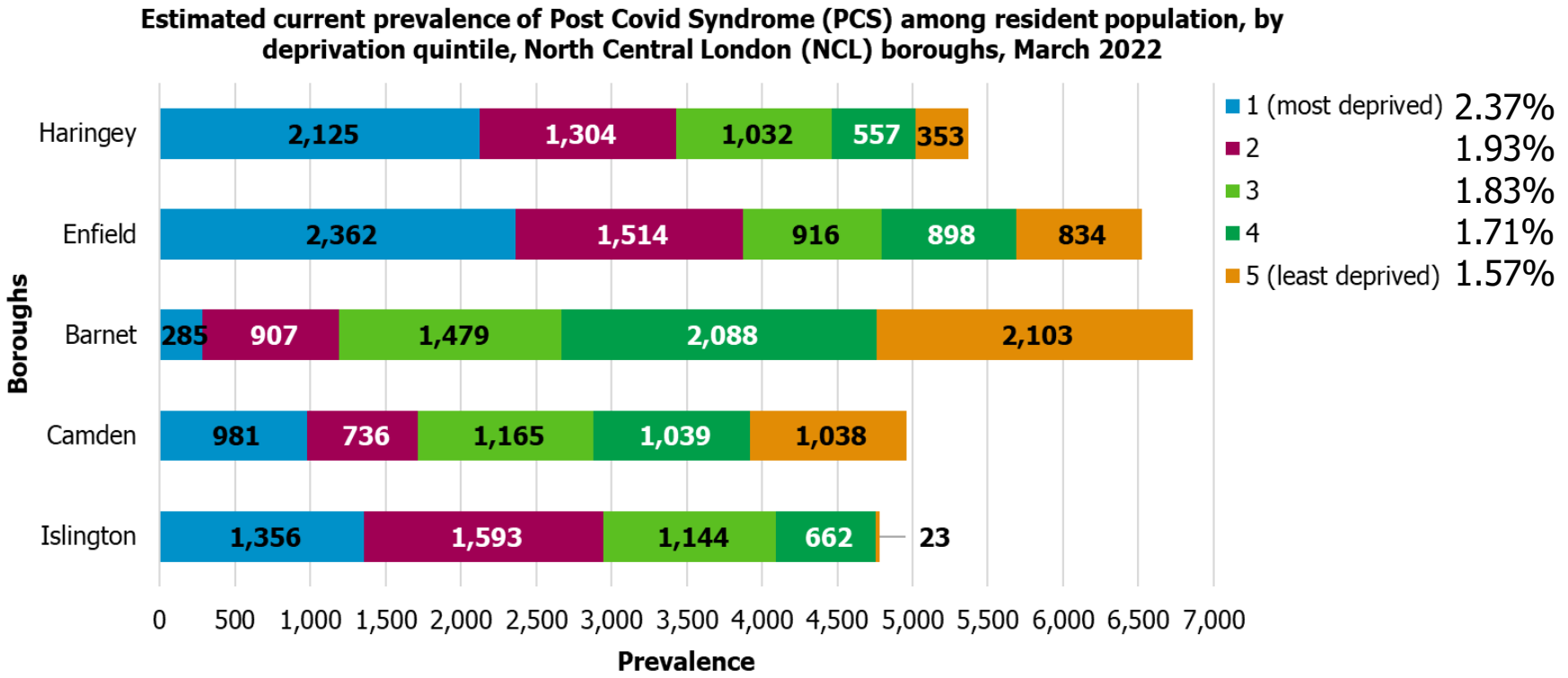


Note: Modelling of current prevalence is based on Office for National Statistics (ONS) Infection Survey data; 0-1 age group has been excluded

Source: ONS population estimates, mid-2019; ONS COVID-19 Infection Survey data, April 2022

- PCS prevalence is estimated to be **highest in working age adults**.
- According to the ONS Infection survey data, prevalence of PCS rises from 0.49% in children 2-11 to **2.73% in those aged 35-49**, falling to 1.10% in the age 70+ (UK, March 2022).
- **Note**: The UK estimates by age group have been applied to the local population estimates in the NCL boroughs to derive local estimates of PCS by age.

NCL estimated prevalence, by deprivation

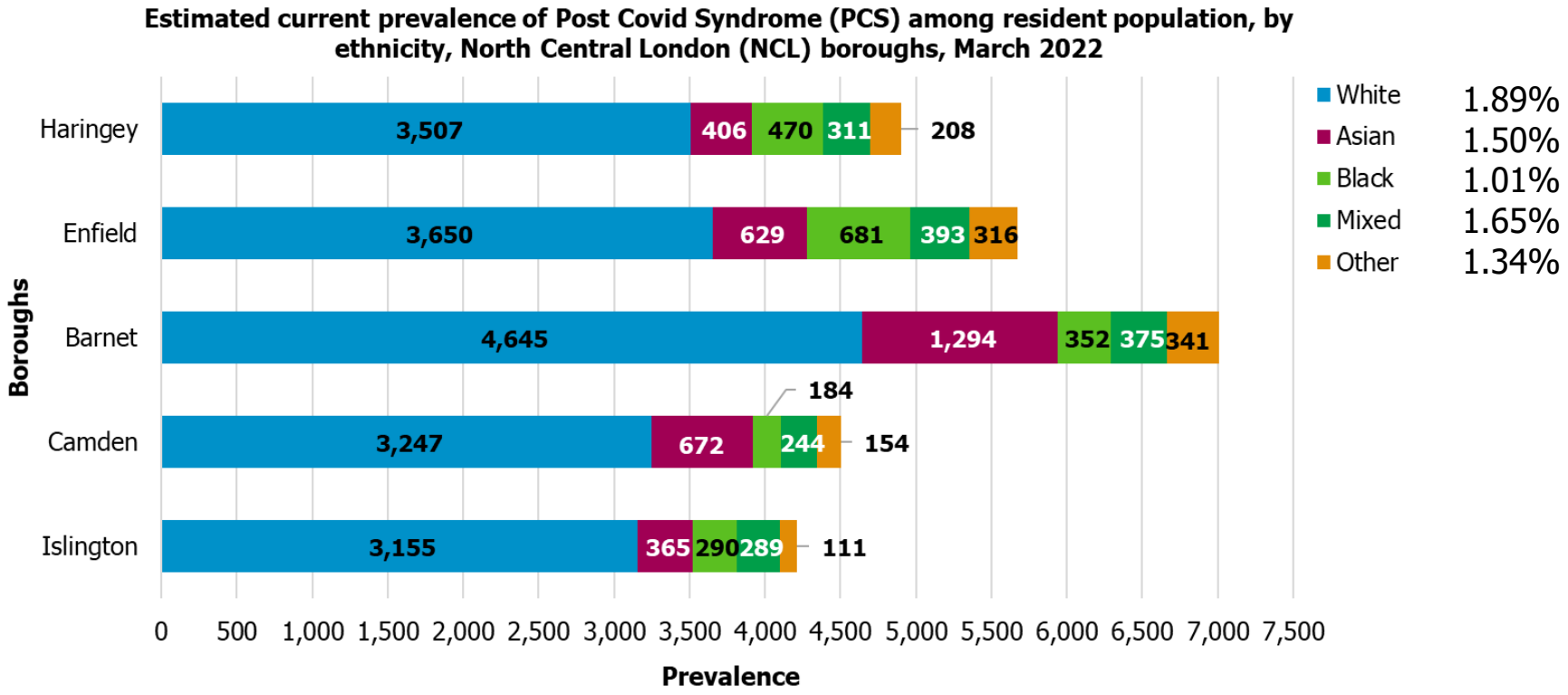


Note: Modelling of current prevalence is based on Office for National Statistics (ONS) Infection Survey data; Deprivation groupings based on IMD (2019) deciles, converted to quintiles as follows: Most deprived = 1, Second most deprived = 2, Third more deprived = 3, Second least deprived = 4 and Least deprived = 5.

Source: ONS population estimates, mid-2019; ONS COVID-19 Infection Survey data, April 2022; English Indices of Deprivation, 2019

- PCS prevalence is estimated to be **higher in more deprived areas.**
- According to the ONS Infection survey data, prevalence of PCS rises from **1.57% in the least deprived areas** to **2.37% in the most deprived areas** (UK, March 2022).
- **Note**: The UK estimates by deprivation have been applied to the local population estimates in the NCL boroughs to derive the local PCS estimates by deprivation.

NCL estimated prevalence, by ethnicity



- According to the ONS Infection survey data, the estimated prevalence of PCS ranges from **1.01% - 1.89%** among various ethnic groups (UK, March 2022), though there is considerable uncertainty in these estimates.
- **Note**: The UK estimates by ethnic group have been applied to the local population estimates in the NCL boroughs to derive local PCS estimates by ethnicity.

Note: Modelling of current prevalence is based on Office for National Statistics (ONS) Infection Survey data

Source: GLA 2016-based ethnic group projections for 2022; ONS COVID-19 Infection Survey data, April 2022

3. Post-Covid pathway and experiences in NCL

This section presents an overview of the Post-Covid pathway in NCL and a summary of key findings from the Healthwatch report on Long COVID in NCL, 2022 (Healthwatch Islington, Healthwatch Camden, Healthwatch Enfield, Healthwatch Haringey and Healthwatch Barnet)

Post-Covid Pathway in North Central London

The Post-Covid pathway in NCL is structured around:

- **Identification** (in acute and primary care)
- **Assessment** in primary care
- **Onward referral** through a single point of access (SPA) to:
  - Specialist UCLH Clinic
    - Specialist secondary care
  - Community rehabilitation
    - Physiotherapy
    - Psychological therapy
    - Fatigue Management
  - Supported self-management and digital platforms

Website:

- **NCL Integrated Post-Covid Syndrome Service**

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NCL Patient Pathway

Identification

Acute

Patients who have been admitted to hospital for acute Covid and followed-up by the acute provider may be identified as having ongoing symptoms. These patients will be assessed by the acute provider and they will make any needed referrals.

Primary care

Patients may present to general practice with ongoing symptoms post acute Covid infection. **Active casefinding** in primary care may identify patients, e.g. follow-up to patients who have been on **Covid Oximetry @home**.

Post-Covid assessment should begin at 4 weeks post-acute diagnosis, and other diagnoses may need to be ruled out at this stage.

Referral for specialist advice should not be delayed for red flag symptoms or if a worsening trend.

Primary care assessment

1.Patients should be invited to complete a **post-Covid syndrome pre-assessment questionnaire** in advance of their appointment

2.Clinical assessment of the patient's symptoms guided by the **NCL Post-Covid syndrome EMIS template** to develop a care plan.

3. Completion of investigations outlined in the **NCL Primary Care Guidance document.** Offer self management advice.

4. If required, completion of a **Post-Covid Service Referral Form**

If red flag symptom(s), refer directly to **UCLH clinic on eRS** or for acute medical input

Other referrals to borough **Post-Covid single point of access**

Referral & safety netting

Single point of access

The borough **SPA** will review the referral and make recommendations about the patient's onward care.

- Referral to the UCLH specialist post-Covid syndrome clinic
- Referred to community therapy for rehabilitation
- Safe to manage in primary care with supported self-management.
- You may be invited to join a borough **virtual Post-Covid MDT meeting** for further discussion and care planning

Note: Please advise patients that if their symptoms improve before their appointment date at UCLH they should cancel it to allow other urgent referrals to be seen quicker.

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Post-Covid Clinics in London

Clinic Status

North Central London

- University College London Hospital Trust (community services being delivered by the BEH, CLCH, CNWL, Royal Free London, Whittington Hospital

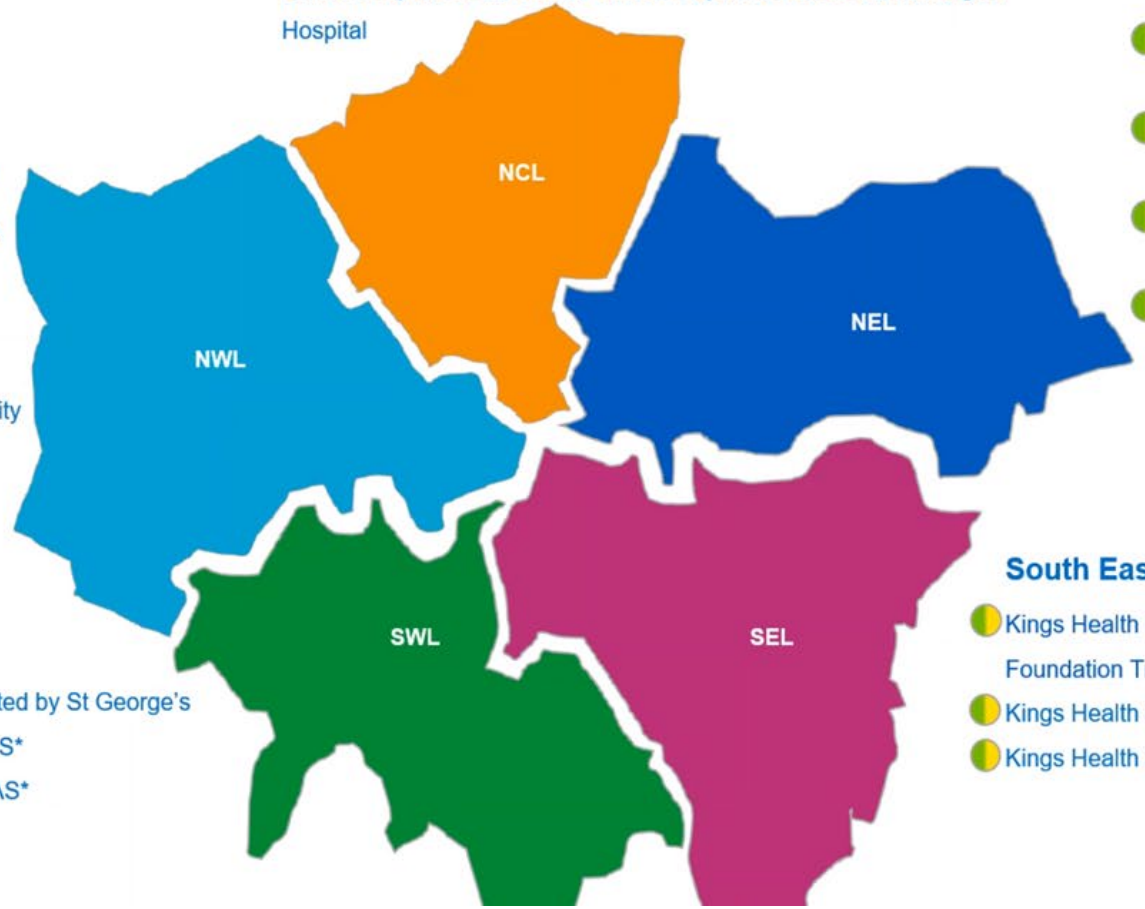
NHS London

North East London

- Homerton University Hospital Foundation Trust
- Barking, Havering and Redbridge University Hospitals NHS Trust
- East London Foundation Trust (in partnership with St Barts)
- North East London Foundation Trust (in partnership with St Barts)

North West London

- Imperial College Healthcare NHS Trust
- Chelsea and Westminster Hospital NHS Trust
- London North West University Healthcare NHS Trust



South West London

- SWL Specialised PCAS* hosted by St George's
- Kingston and Richmond PCAS*
- Merton and Wandsworth PCAS*
- Croydon PCAS*
- Sutton PCAS*

South East London

- Kings Health Partners (Guys and St Thomas NHS Foundation Trust)
- Kings Health Partners (Kings College Hospital)
- Kings Health Partners (Princess Royal University Hospital)

Resident experiences of Long COVID in NCL

The **Healthwatch teams in Camden, Islington, Barnet, Haringey and Enfield** recently came together to gather insight on local NCL residents' experiences of living with Long COVID. This was achieved through an anonymous online survey, 1-2-1 interviews and community focus groups – reaching 300 people in total.

The report covers:

- Impact on health (physical health, mental health and wellbeing)
- Impact on life (employment and job security, home life)
- Experiences with the healthcare system (accessing the pathway, referrals, diagnosis, useful interventions)

The report makes a number of **recommendations** to parts of the system across NCL – primary care, the CCG, the specialist clinic, community teams, councils and employers. The full report and recommendations can be found here: People's Experience of Long COVID in North Central London, April 2022

A summary of some of the key findings follows.

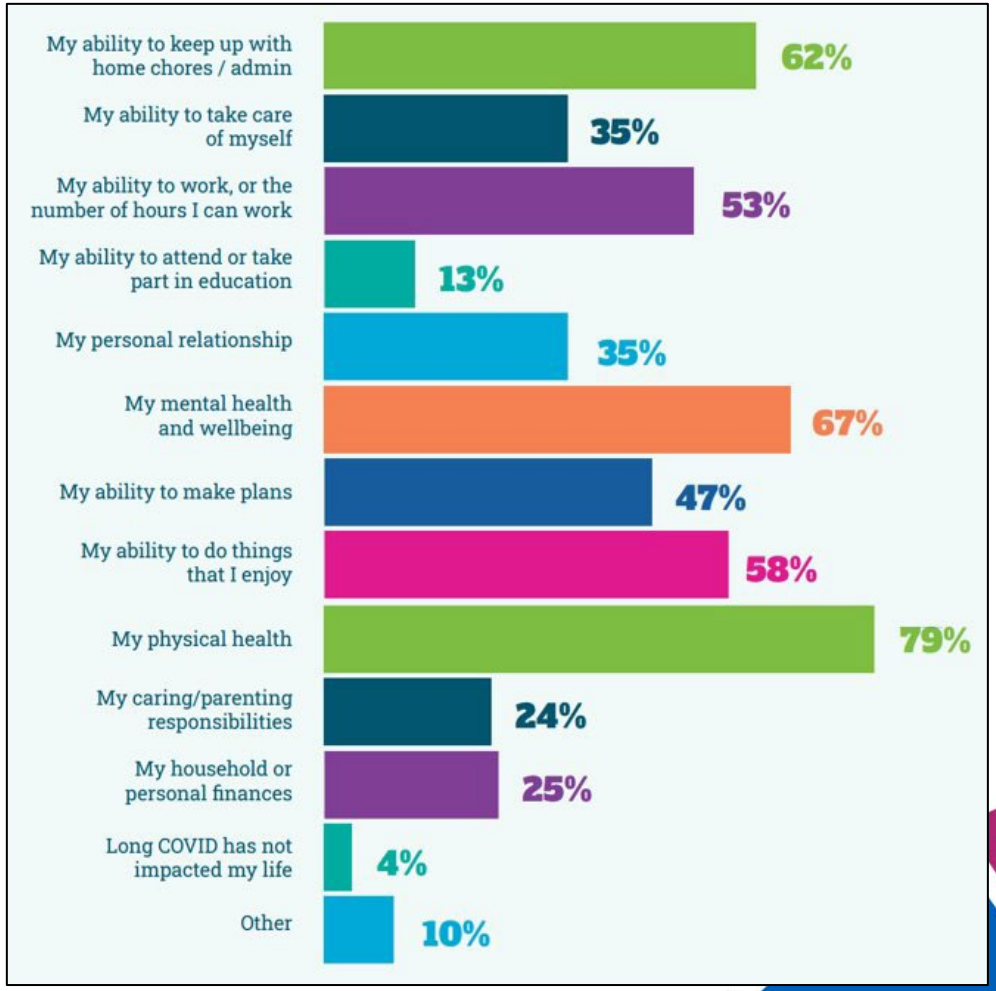
Resident experiences of Long COVID in NCL – Impact on Life

- 79% of respondents reported an impact on physical health, while 67% reported an impact on mental health and wellbeing.
- Respondents reported a wide range of impacts on all areas of life: their ability to work (53%), do house chores (62%), their personal relationships (35%), caring responsibilities (24%), their education (13%) and ability to do things they enjoy (58%).

> Not being able to work, take care of my household or family is very frustrating and relying on others is demeaning.
> Barnet Resident

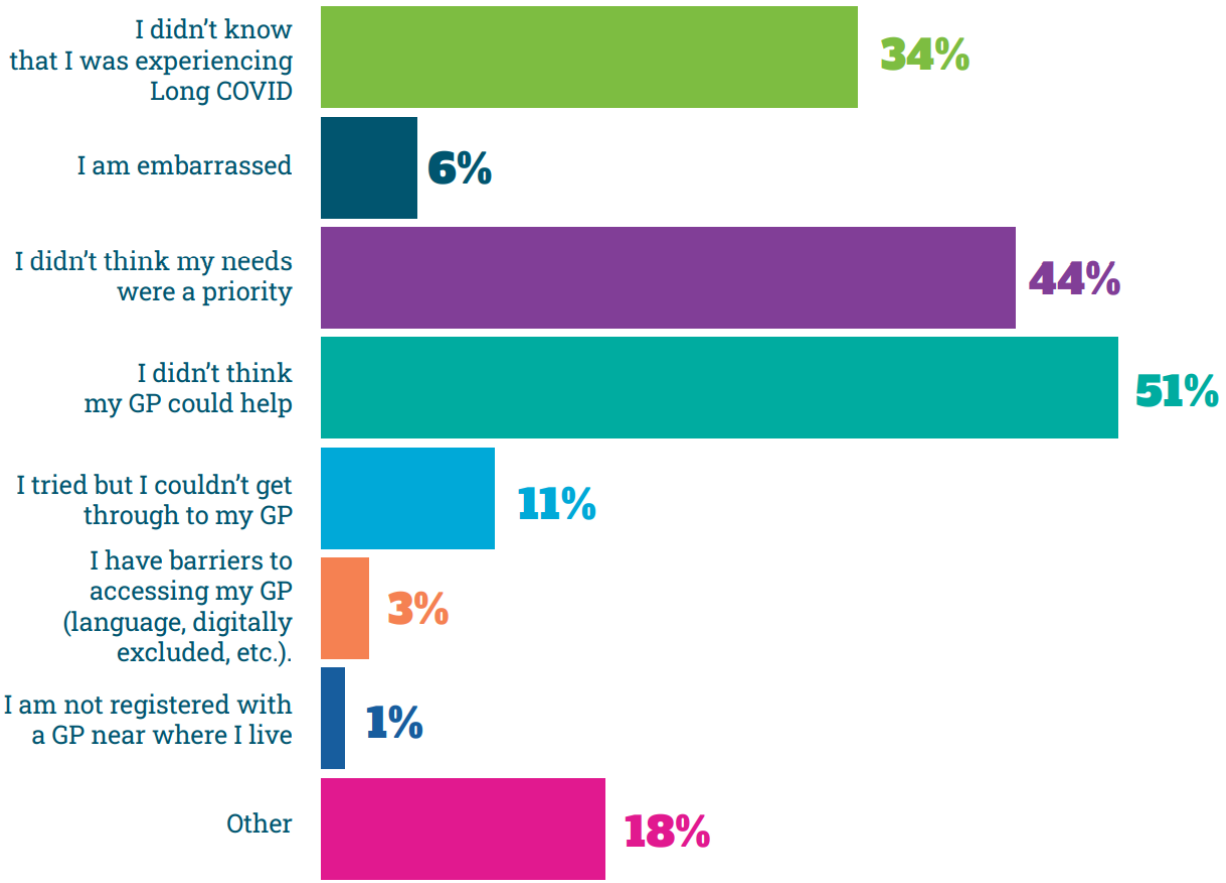
> I have had to drop down my hours at my job due to COVID.
> Camden Resident

> Can't do the things I used to be able to do - even though I was young, fit and healthy before catching COVID.
> Enfield Resident



Reference : Healthwatch: People's Experience of Long COVID in North Central London April 2022

Resident experiences of Long COVID in NCL – Experiences with the Healthcare System



- Two thirds (67%) of respondents had seen a GP or healthcare professional about their symptoms
- The remaining one third (33%) had not done so, and their reasons are shown here (left).
- 51% did not think their GP could help, while 44% did not think their needs were a priority, a common sentiment during the pandemic lockdowns.
- 34% did not know that what they were experiencing was Long Covid.
- Of the 67% who had seen a GP or healthcare professional, 61% had received a formal diagnosis.
- Of those who had received a formal diagnosis, 55% reported the diagnostic process took more than four months.

Reference : Healthwatch: People's Experience of Long COVID in North Central London April 2022

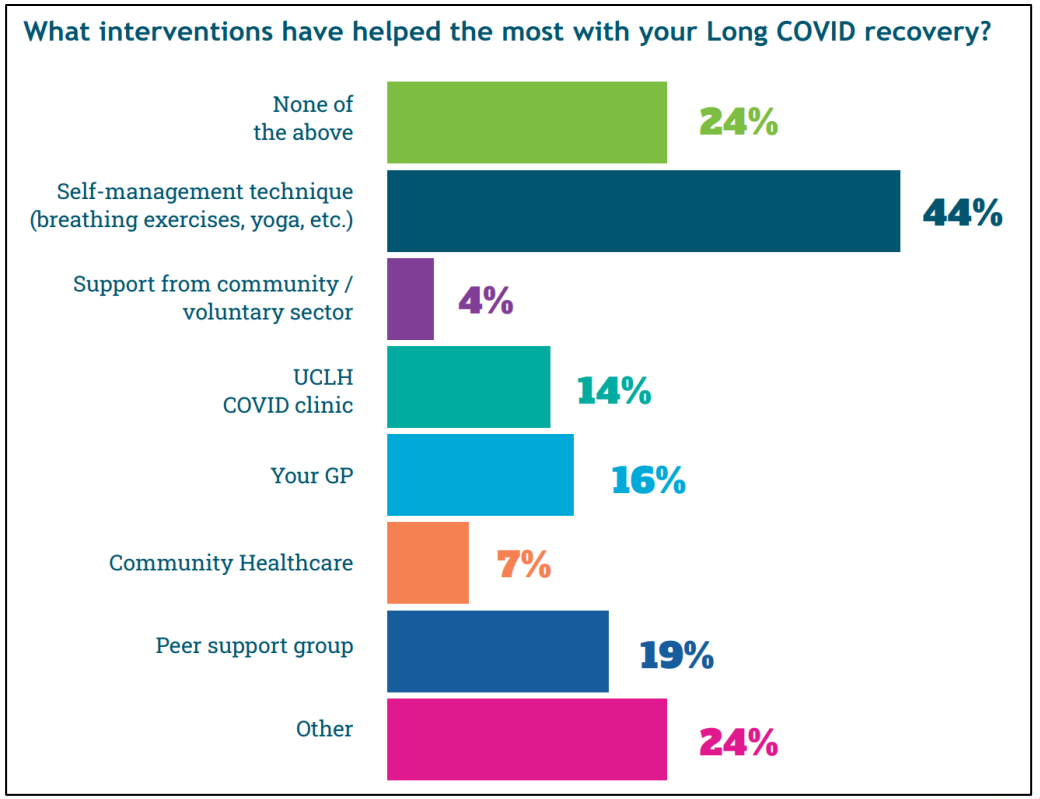
Resident experiences of Long COVID in NCL - Healthcare Support and Interventions

- Half (51%) of respondents reported difficulties getting the right support, with reports of long waiting times, delays and inadequate communication.

- The most helpful intervention reported was self-management techniques (44%) and 61% of respondents had found this information themselves.

> I was desperate to make progress...
> Didn't want to just sit around being helpless.
> Camden Resident

> There are long gaps between having COVID, seeing GP, referral bloods & x-ray, being seen etc so I carried out my own research to try and plug the gap. It helped me get a rough idea of what type of things I could / should do at home to help manage the condition.
> Camden Resident



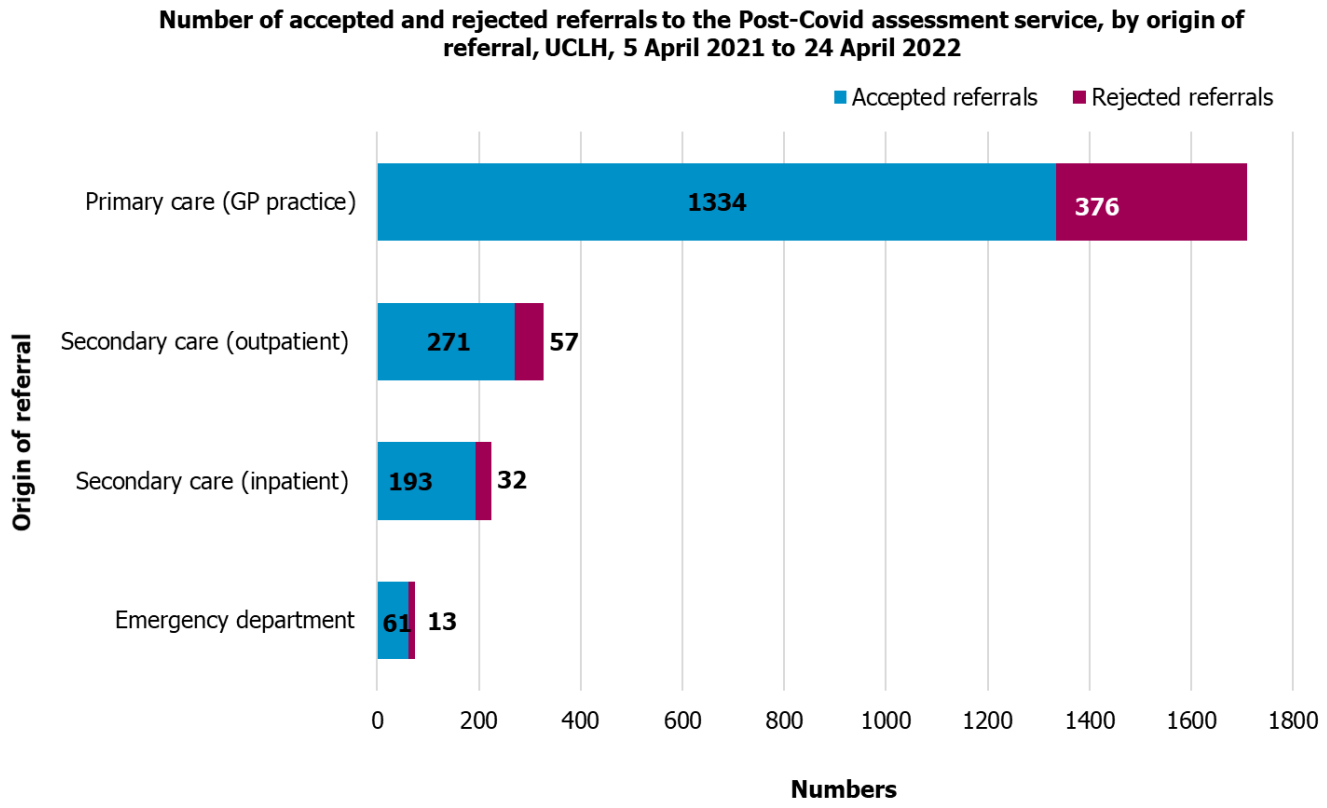
Reference : Healthwatch: People's Experience of Long COVID in North Central London April 2022

4. Post-Covid specialist clinic data

This section presents the overview of referrals, initial clinical assessments and completed assessments in the Post-Covid assessment service, including pathway(s) followed by patients after completion of their assessment in the reporting period (5 April 2021 – 24 April 2022).

Data source: UCLH Long-Covid Clinic Report, April 2022

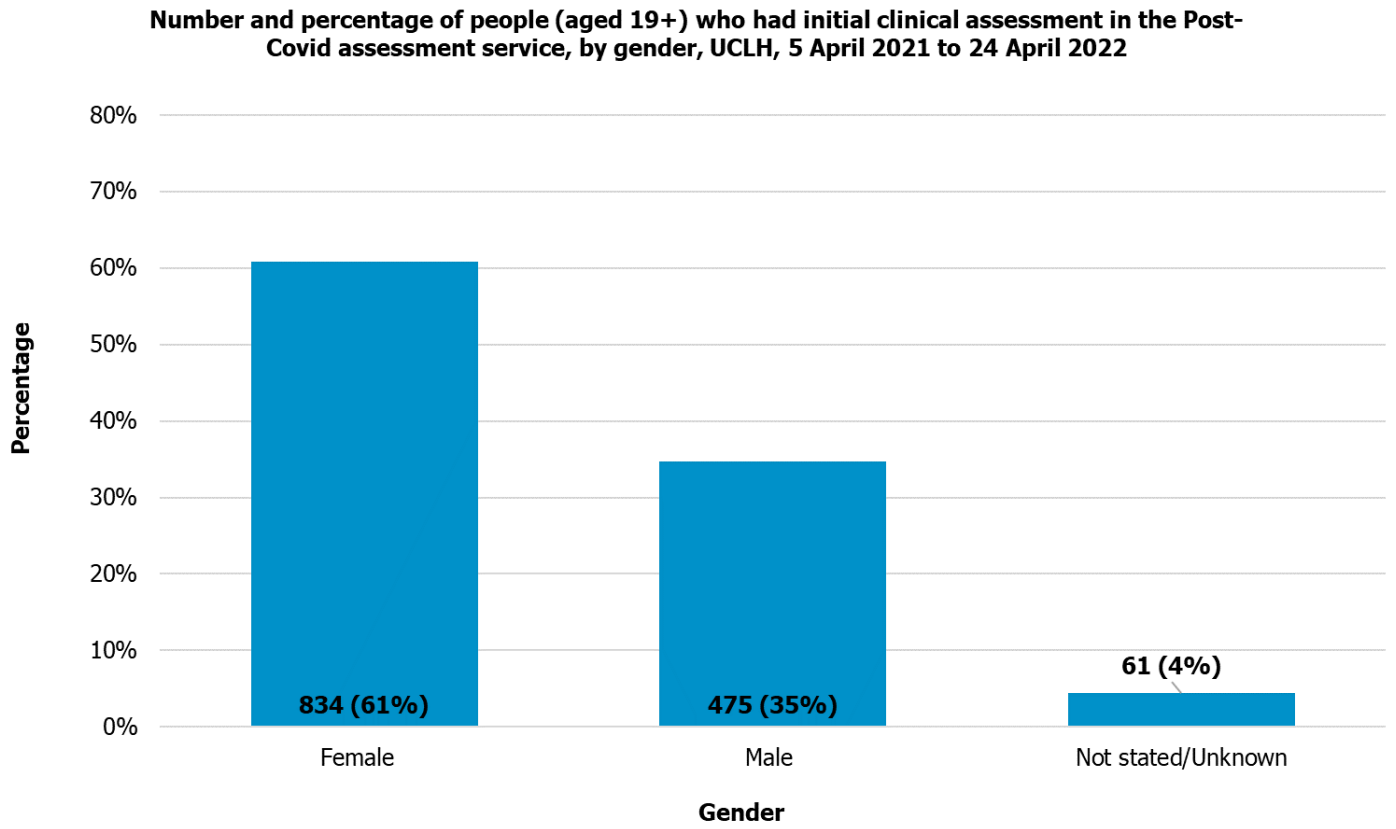
Specialist clinic – source of referral



- Out of **2,337** total referrals made to the Post-Covid assessment service between 5 April 2021 to 24 April 2022, **80% (1,859)** were accepted.
- Out of total accepted referrals Primary care accounted for **72% (1,334).**

Source: UCLH Long-Covid Clinic Report, April 2022

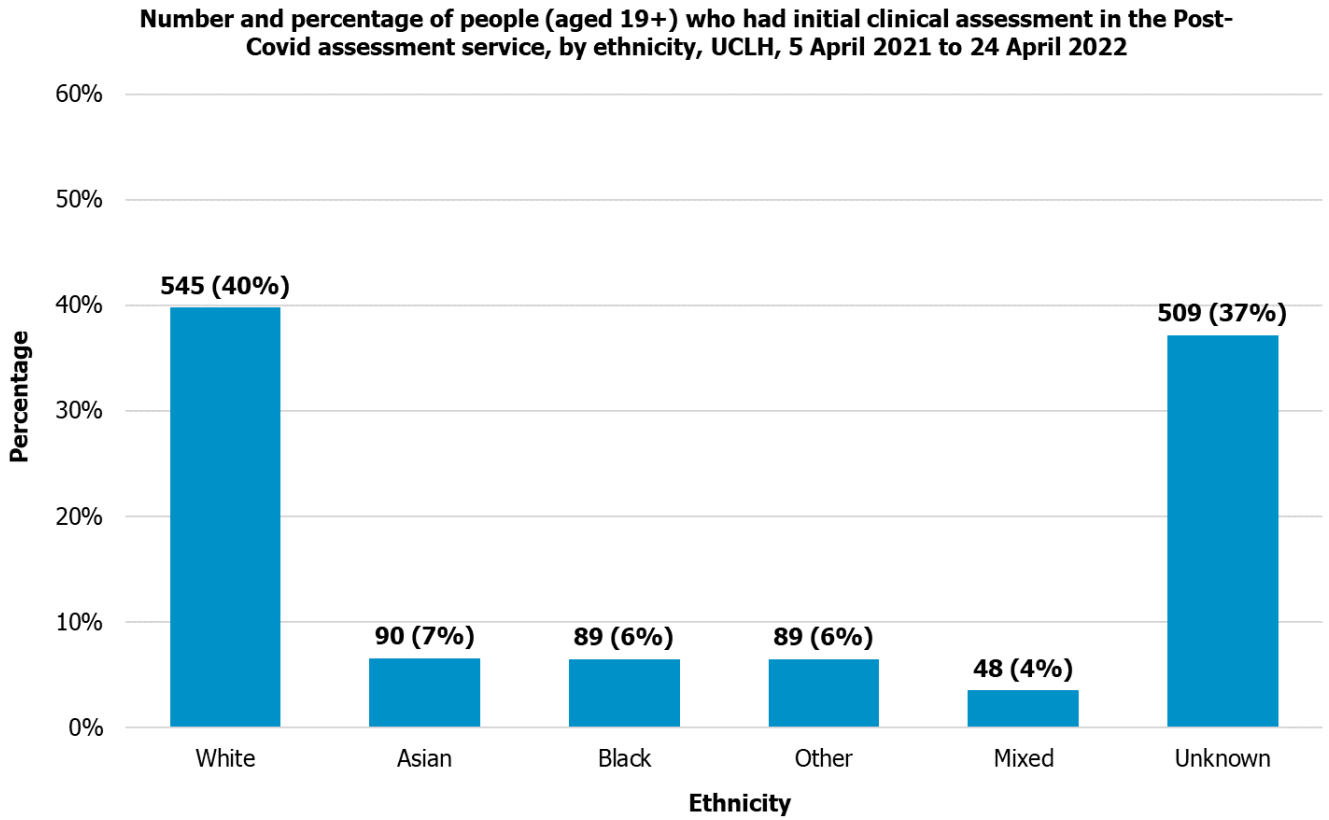
Specialist clinic - gender



Source: UCLH Long-Covid Clinic Report, April 2022

- A total of **1,370** patients had an initial clinical assessment between 5 April 2021 to 24 April 2022.
- The majority (**61%**) of patients were female (834); **35%** of patients were male (475) and the remaining **4%** (61) did not have their gender recorded.
- This pattern aligns with expectations from the prevalence estimates

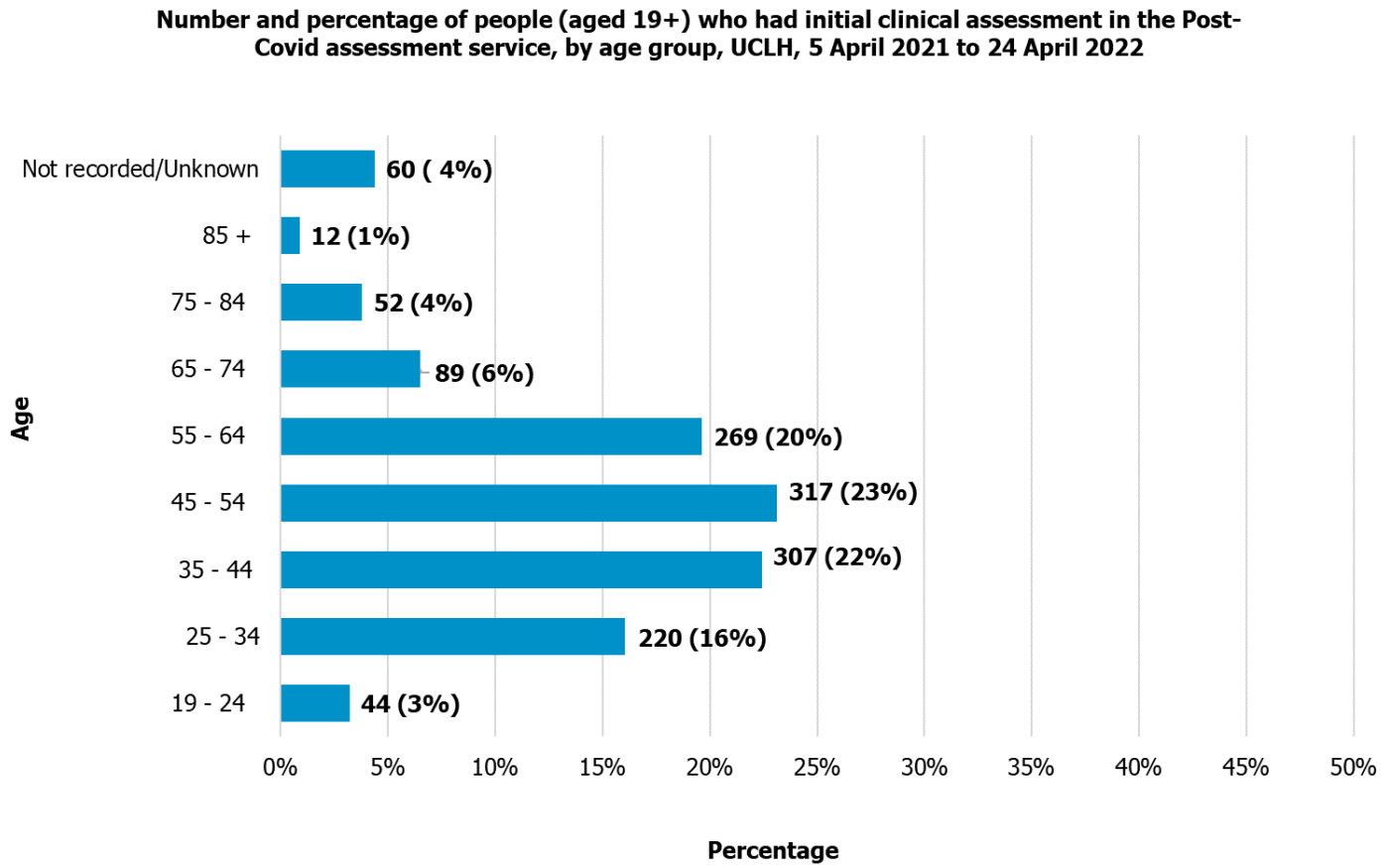
Specialist clinic - ethnicity



Source: UCLH Long-Covid Clinic Report, April 2022

- Just over a third of patients **(37%)** did not have their ethnicity recorded, which makes it difficult to draw conclusions.
- Of all patients who had initial clinical assessment, **40%** were recorded as White. The remaining **23%** were ethnic minorities.
- **Note:** The ethnic category "White" does not specify whether this is White British or Other White.

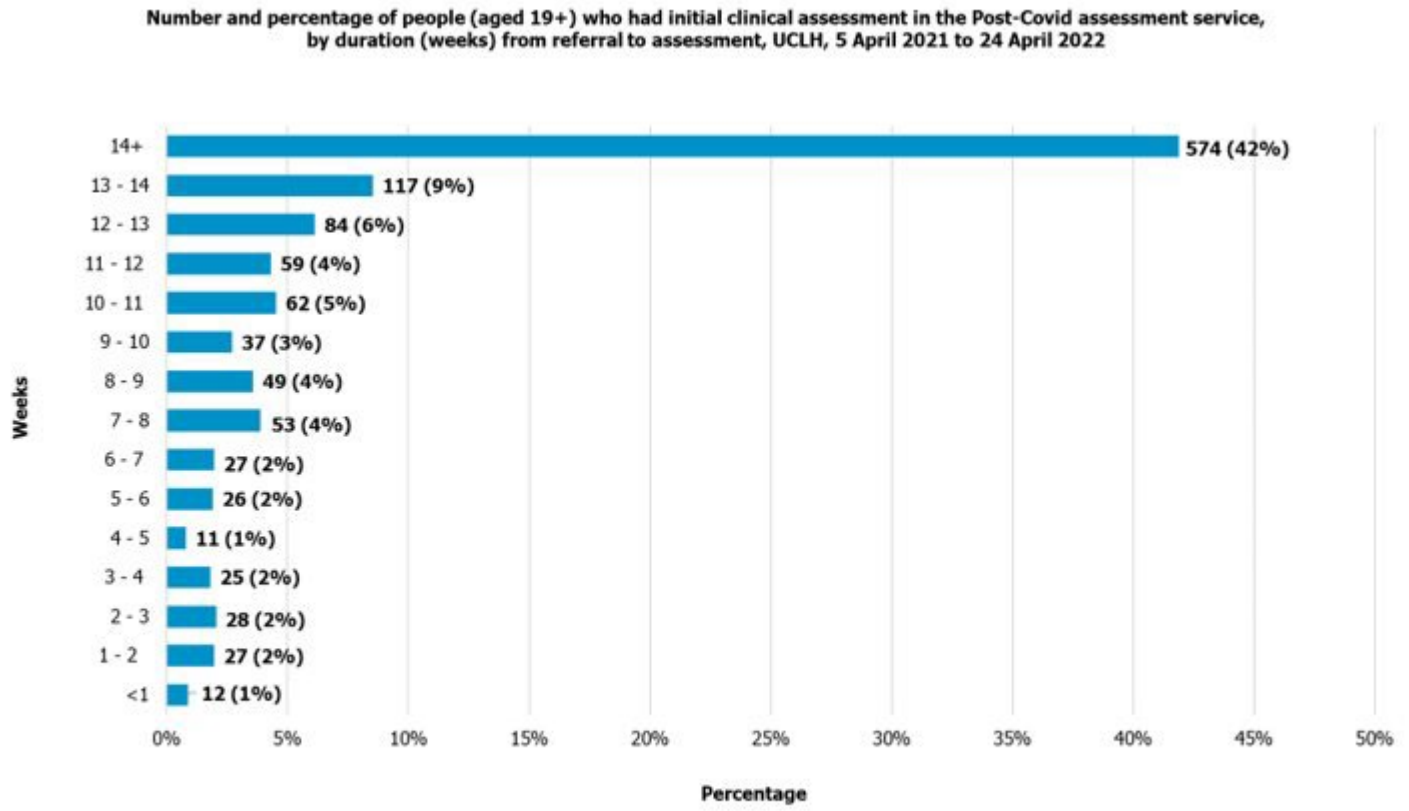
Specialist clinic – age



Source: UCLH Long-Covid Clinic Report, April 2022

- Over one third of patients assessed were aged **25-64 (81%).**
- This pattern aligns with expectations from prevalence estimates.
- There were very few younger patients aged **19-24 (3%)** and older patients aged **65 and over (11%).** The remaining **4%** did not have their age recorded.

Specialist clinic - duration from referral to assessment

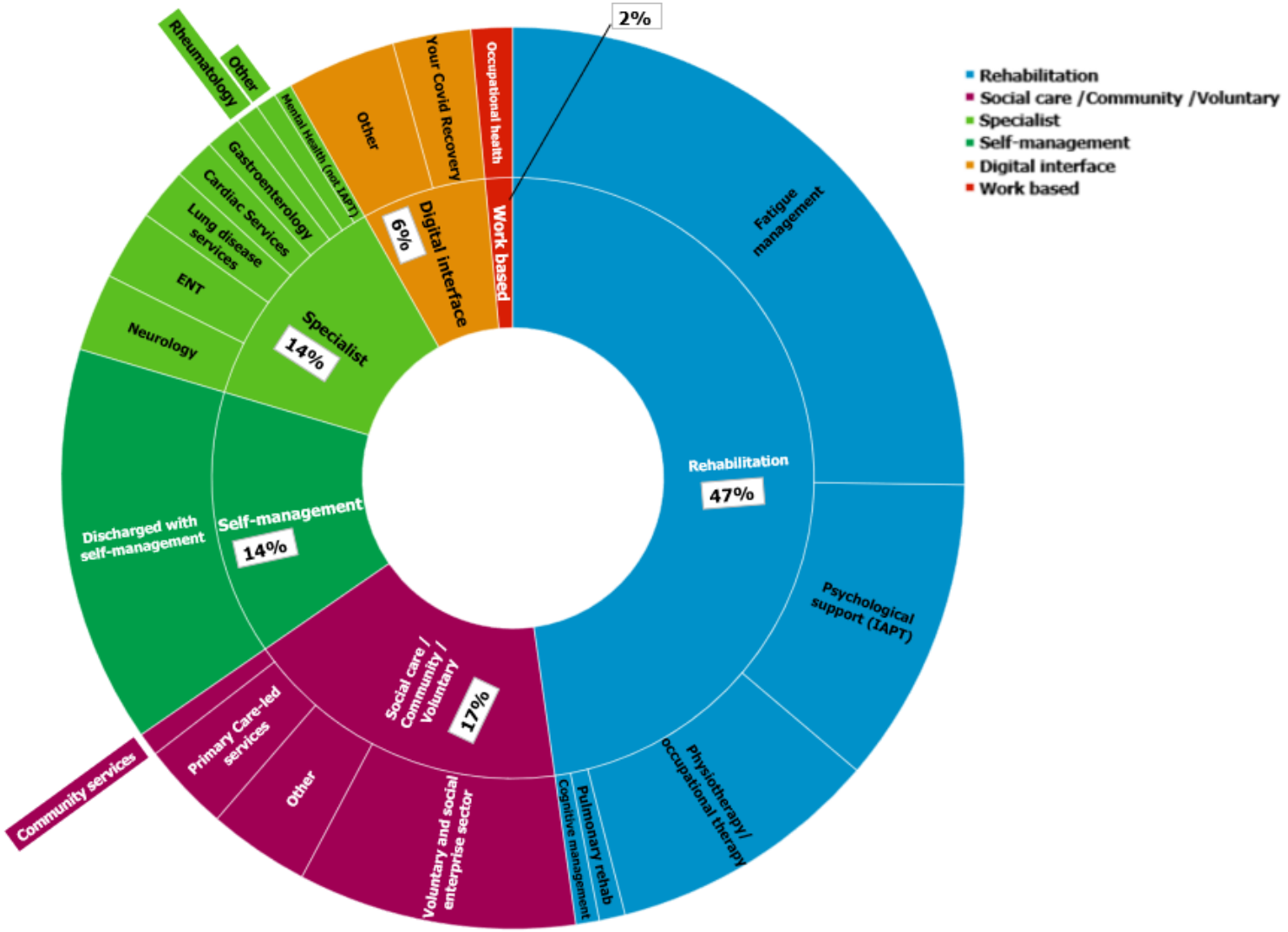


Note: 179 patients who were not placed on a referral waiting list have been excluded from this chart, hence the percentages won't add up to 100.

Source: UCLH Long-Covid Clinic Report, April 2022

- About **13% of patients (179)** had a standard post inpatient follow up, whereby the patients were not placed on a referral waiting list.
- For all other pathways, the majority of patients **(42%)**, waited over 14 weeks from the point of referral to initial clinical assessment.

Specialist clinic – onward pathways



- A total of **1,585** patients had completed their assessments in the Post Covid assessment service between 5 April 2021 to 24 April 2022.
- A large proportion of patients who completed their assessment went on to receive rehabilitation **(47%)**, followed by social care/community & voluntary **(17%),** self-management and specialist care **(14% respectively)**, as of 24 April 2022.
- Note: Any given patient could have received support from more than one pathway service during the reporting period.

Note: Some of the sub-pathways are not displayed in the chart due to small numbers
Source: UCLH Long-Covid Clinic Report, April 2022

Specialist clinic – summary table

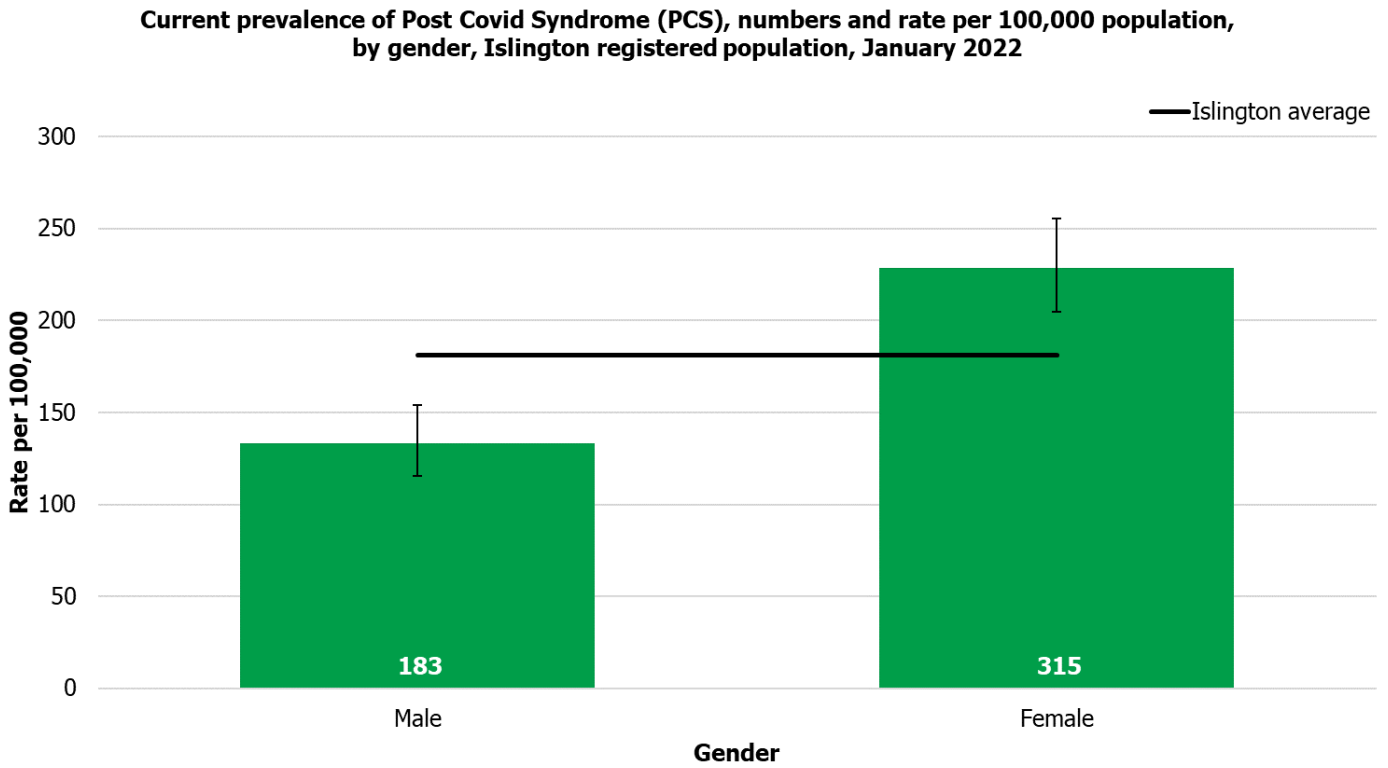
Total number of **referrals** to the post-COVID assessment service in the reporting period (5 April 2021 – 24 April 2022)	**2,337**
Total number of patients who have had **completed assessments** in the post covid assessment service (5 April 2021 – 24 April 2022)	**1,585**
Total number of **follow up appointments** undertaken in the reporting period (5 April 2021 – 24 April 2022)	**1,071**
Total number of patients who have had an **initial clinical assessment** in the post covid assessment service (5 April 2021 – 24 April 2022)	**1,370**
Total number of patients still **waiting for an initial clinical assessment** as of 24 April 2022	**244**
Total number of patients from **deprived area** who had initial clinical assessment in the reporting period (5 April 2021 – 24 April 2022) [Deprived area - refers to those area defined as 1 and 2 in the IMD decile rank].	**287 (21%)**

5. Borough Analysis: Islington

This section presents the overview of recorded prevalence of Post Covid Syndrome (PCS) and GP referrals to PCS clinics in Islington, by age, gender, ethnicity, deprivation and geographical level (primary care network [PCN]) where appropriate.

Data source: Commissioning support units (CSU) dataset, January 2022

Recorded prevalence, by gender, Islington

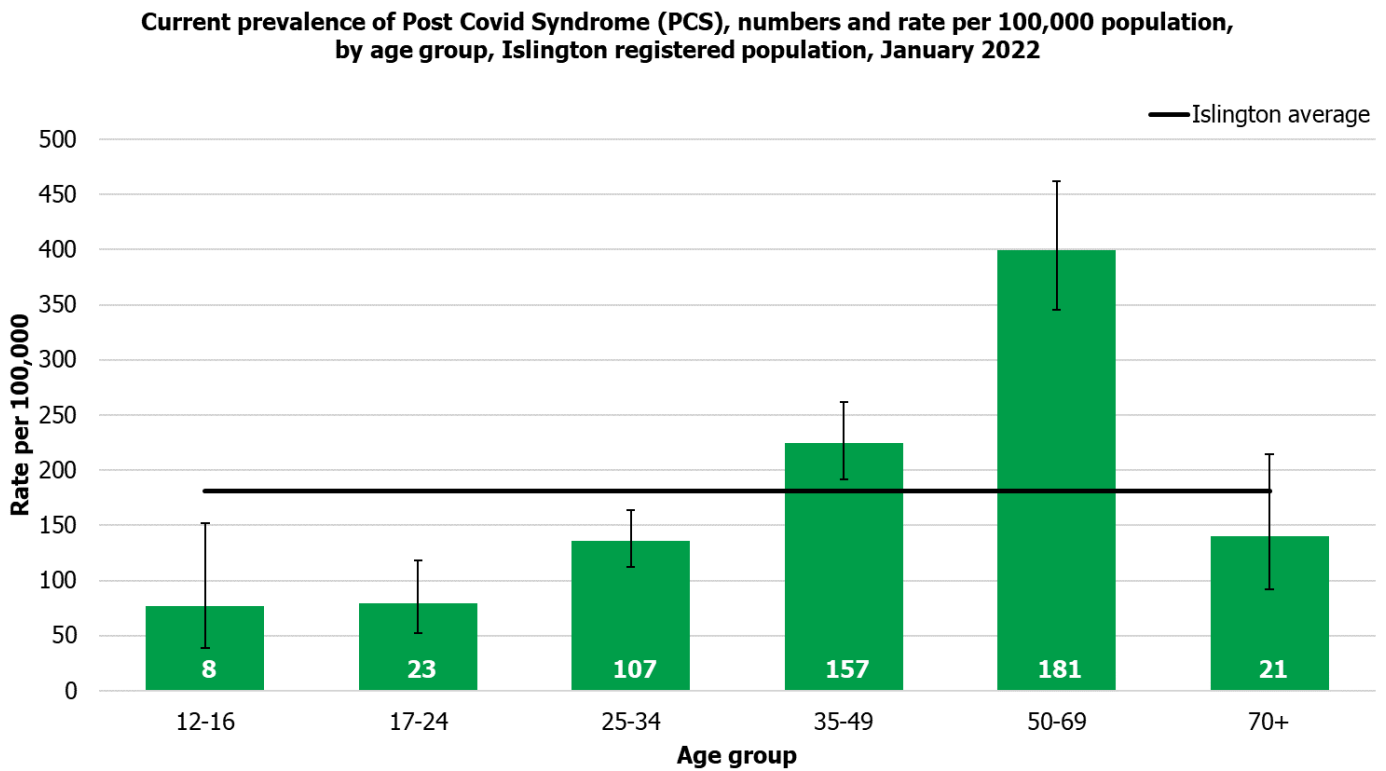


Note: 19 people recorded as having unknown gender have been excluded from this analysis

Source: Commissioning support units (CSU) dataset, January 2022

- The recorded prevalence of PCS is 181 per 100,000 registered population in Islington as of January 2022.
- The recorded prevalence among females (229 per 100,000) is almost double compared to males (133 per 100,000).
- The association with gender aligns with prevalence estimates that suggest higher prevalence in females.

Recorded prevalence, by age, Islington

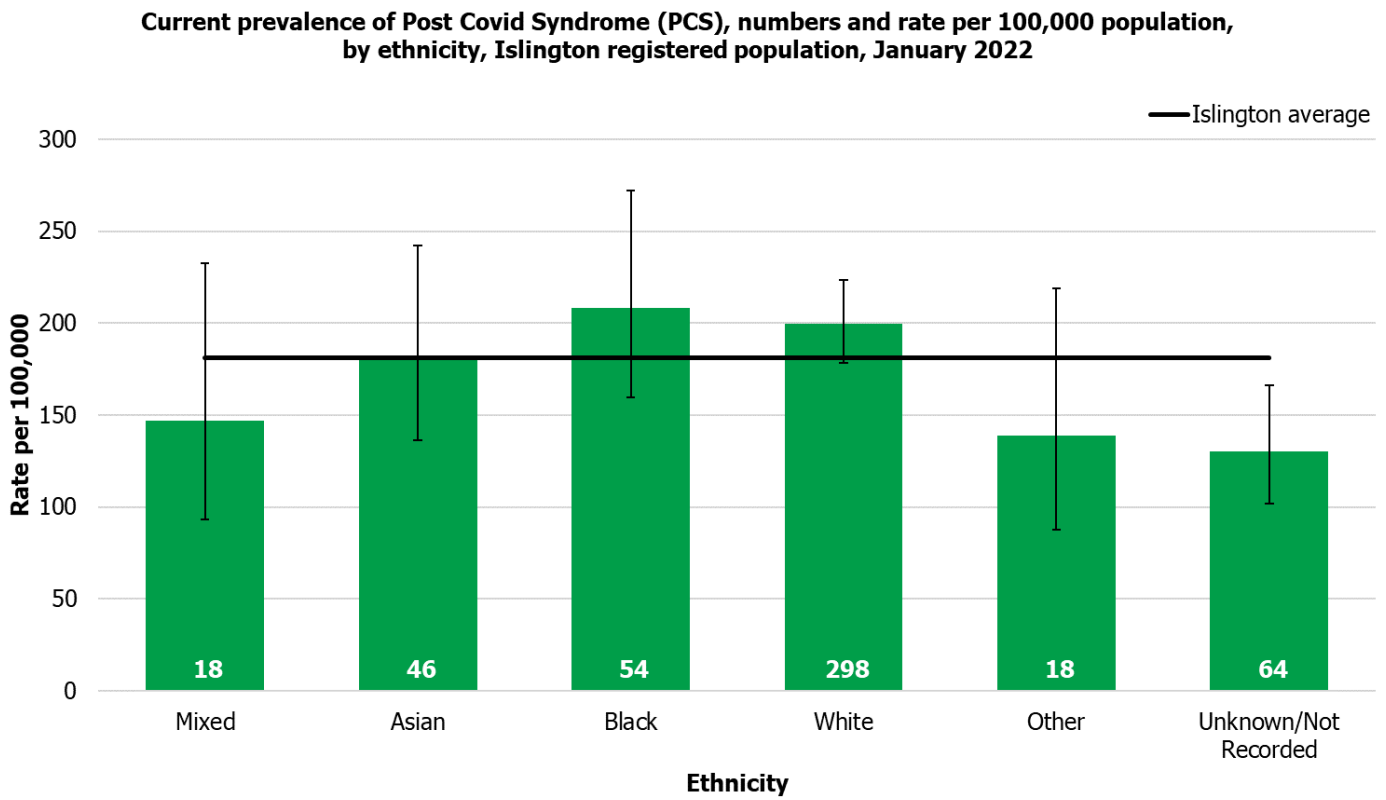


Note: Age group 0-11 has been excluded from this analysis due to small numbers

Source: Commissioning support units (CSU) dataset, January 2022

- The recorded prevalence of PCS is significantly higher among those aged 35-49 (224 per 100,000) and 50-69 (400 per 100,000), compared to the Islington average (181 per 100,000).
- The recorded prevalence of PCS is significantly lower among those aged 12-34, compared to the Islington average.
- The association with age aligns with prevalence estimates that suggest higher prevalence in middle-aged adults.

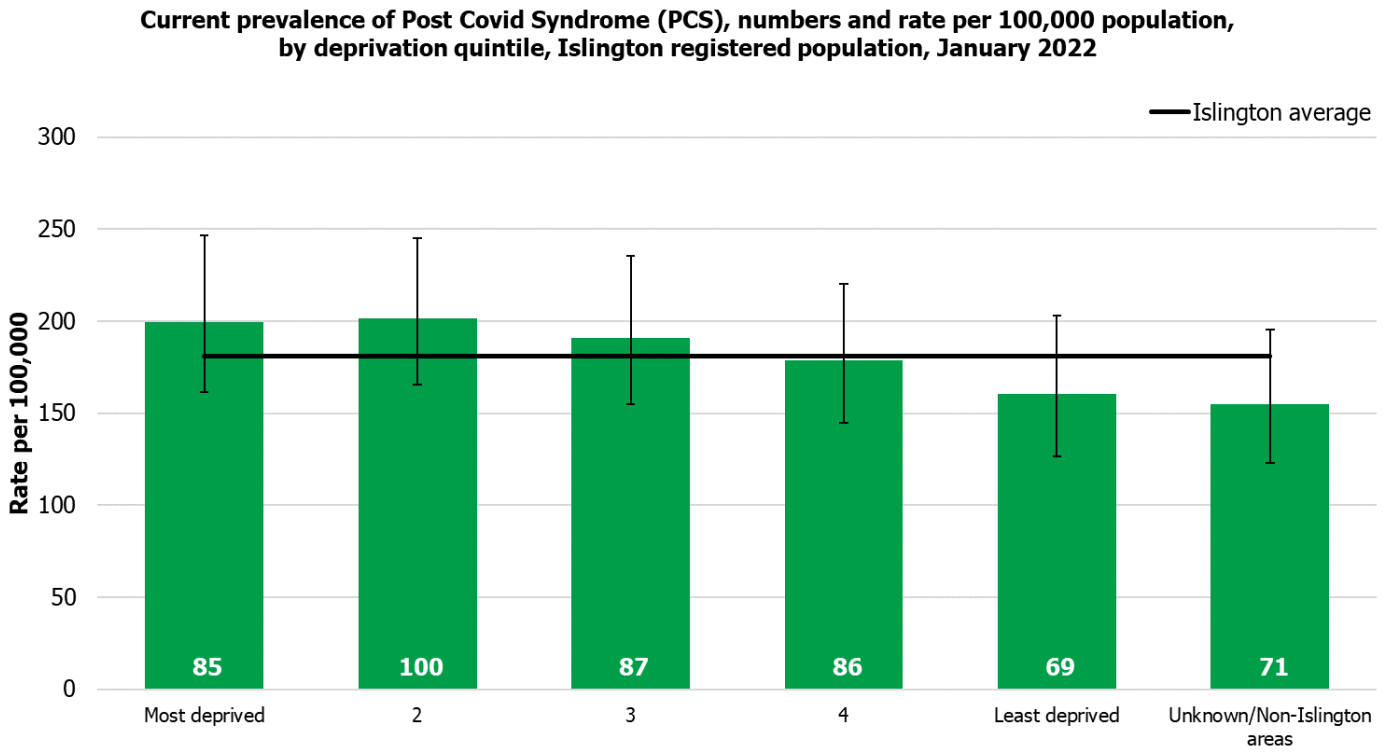
Recorded prevalence, by ethnicity, Islington



- The recorded prevalence of PCS do not vary significantly with ethnicity.

Source: Commissioning support units (CSU) dataset, May 2021

Recorded prevalence, by deprivation, Islington

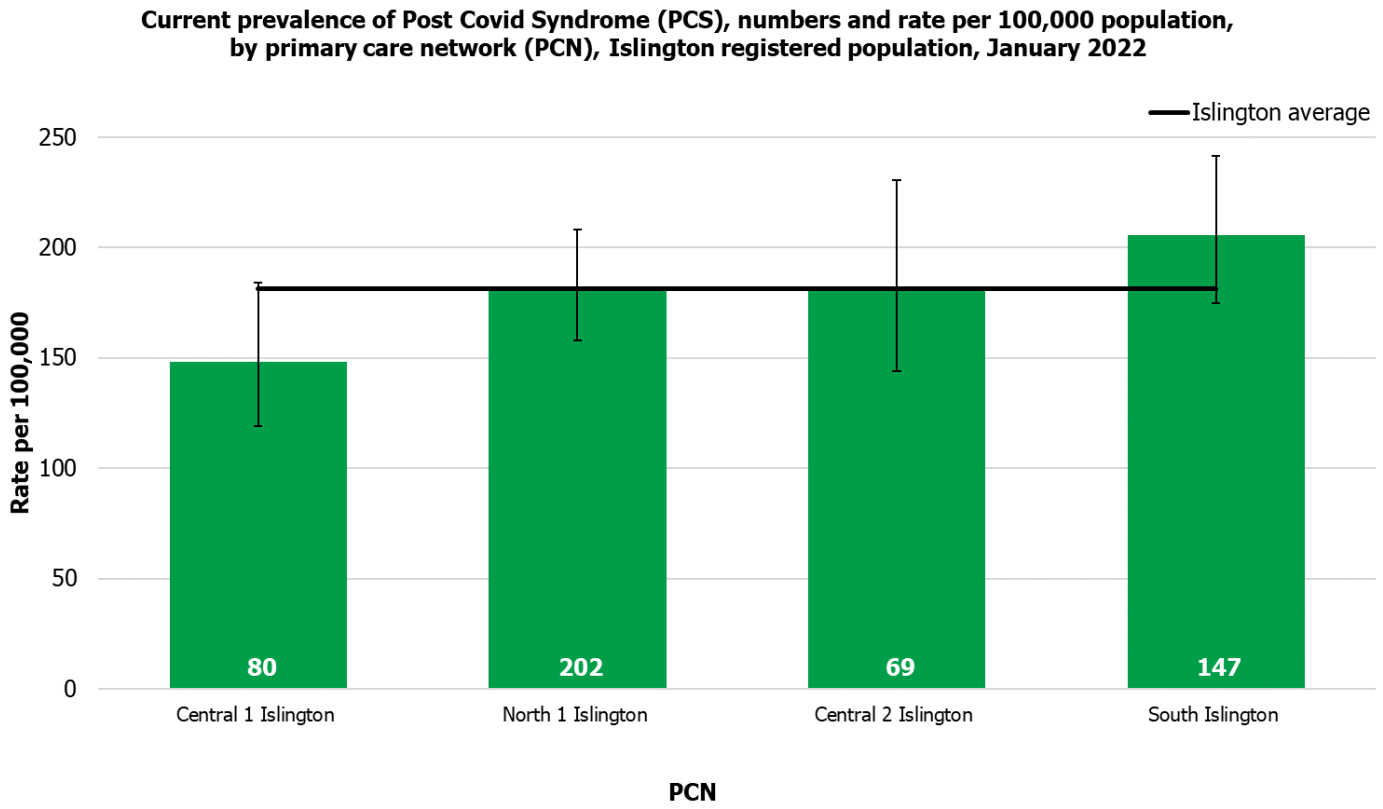


Note: Deprivation groupings based on IMD (2019) deciles, converted to quintiles as follows: Most deprived = 1, Second most deprived = 2, Third more deprived = 3, Second least deprived = 4 and Least deprived = 5.

Source: Commissioning support units (CSU) dataset, January 2022

- There are higher rates of recorded PCS prevalence in more deprived areas, but this is not statistically significant, compared to the Islington average (181 per 100,000).
- Prevalence estimates suggest we would expect to see higher prevalence in more deprived areas.

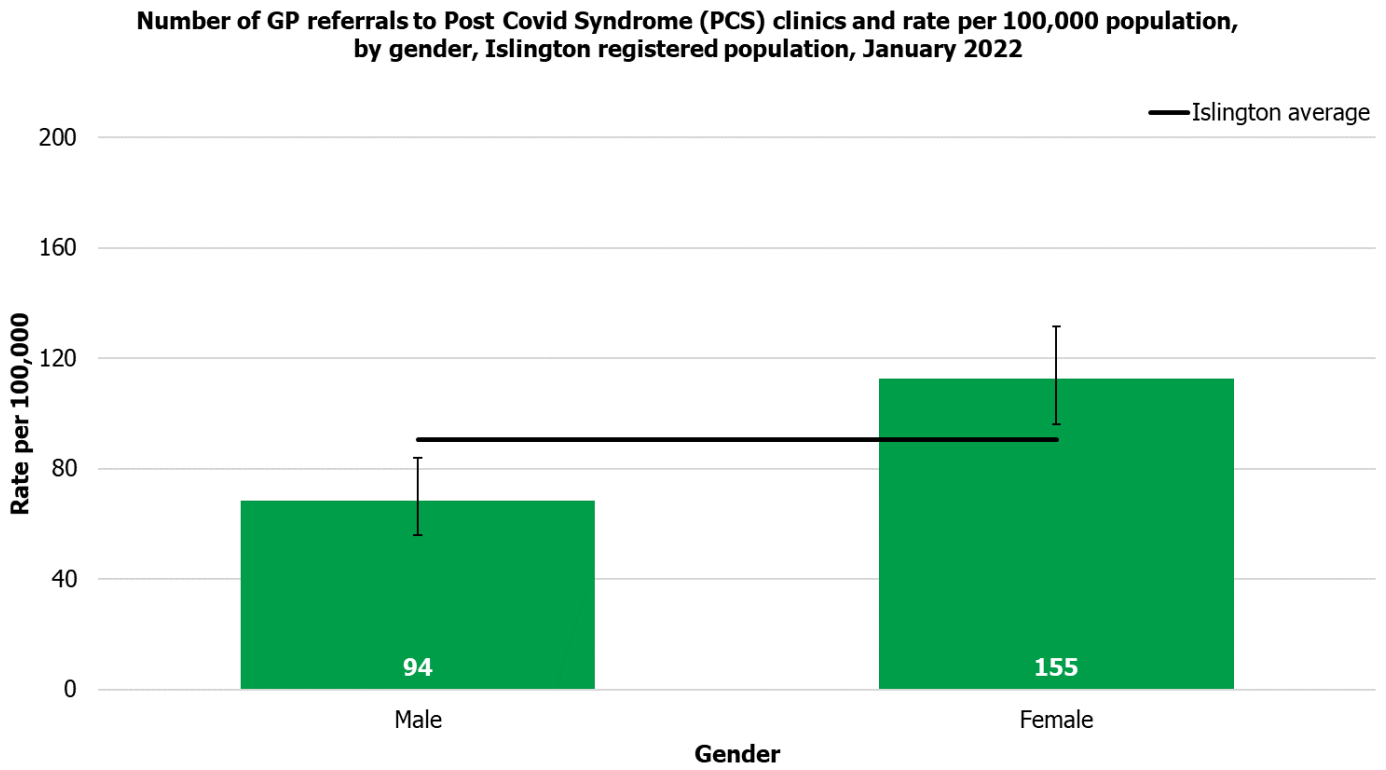
Recorded prevalence, by primary care network (PCN), Islington



Source: Commissioning support units (CSU) dataset, January 2022

- There is variation in recorded PCS prevalence between Islington PCNs, but this is not statistically significant, compared to the Islington average (181 per 100,000).
- The rate of PCS across Islington PCNs ranges from 148 to 205 per 100,000.

GP referrals, by gender, Islington

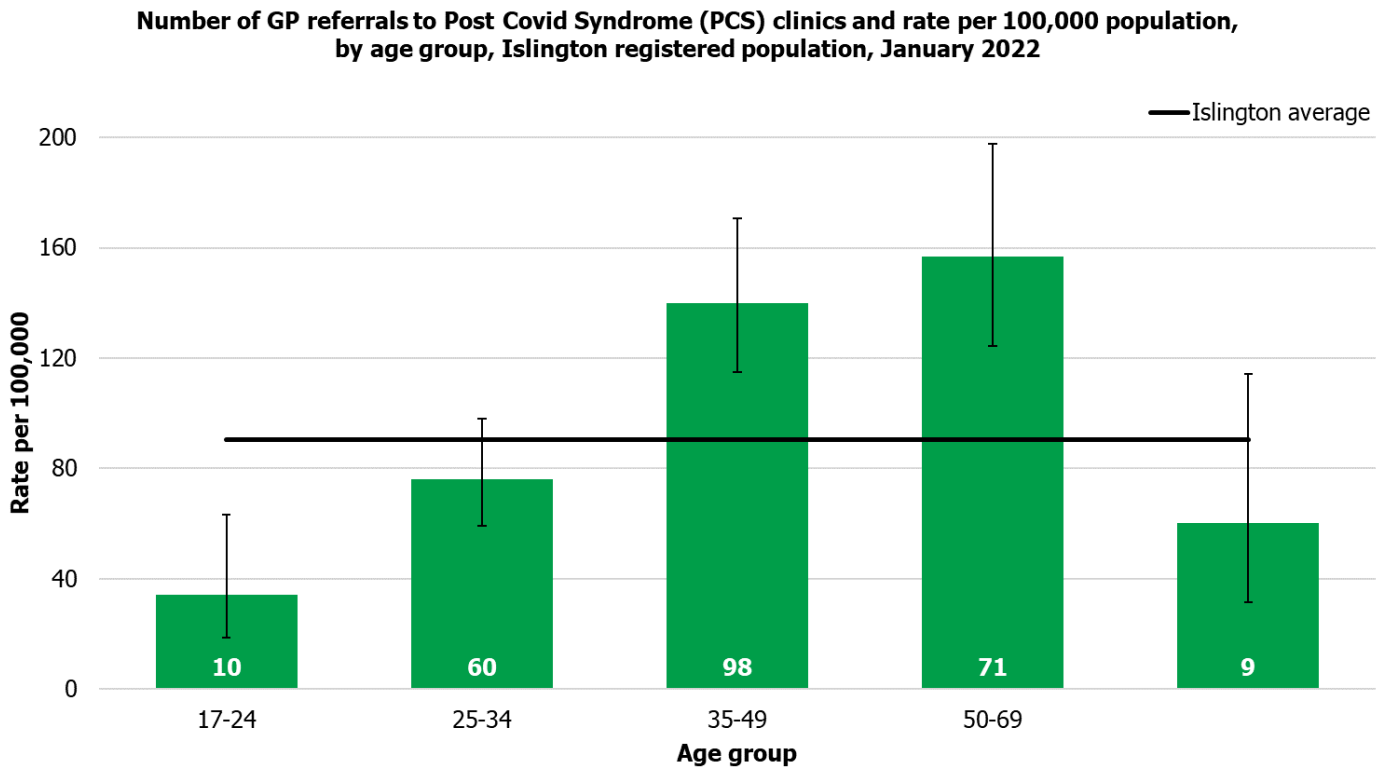


Note: 19 people recorded as having unknown gender have been excluded from this analysis

Source: Commissioning support units (CSU) dataset, January 2022

- The rate of GP referrals to PCS clinics is 91 per 100,000 registered population in Islington as of January 2022.
- The GP referral rates among females (113 per 100,000) is almost double compared to males (69 per 100,000).
- The higher referral rate in females aligns with the higher estimated prevalence and recorded prevalence in females.

GP referrals, by age, Islington

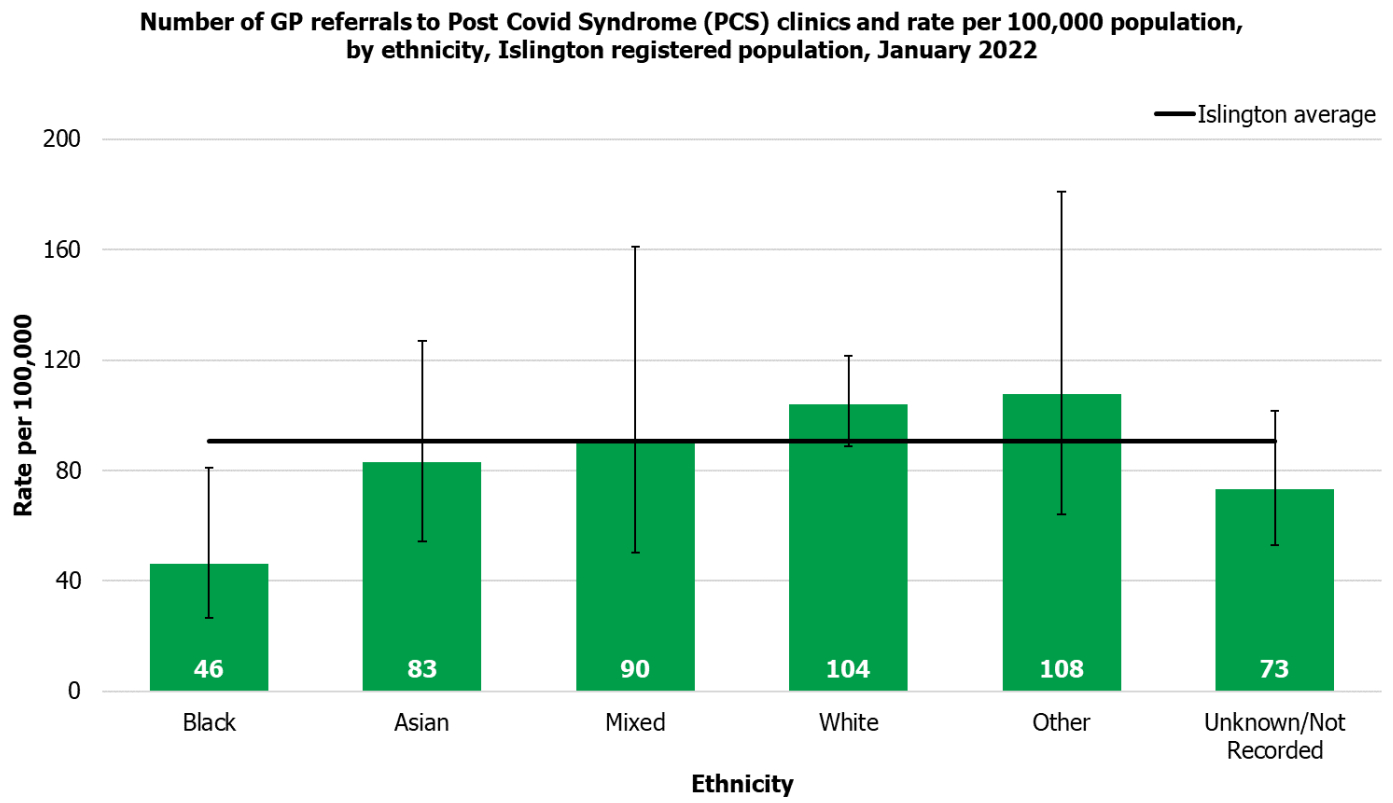


Note: Age group 0-16 have been excluded from this analysis due to small numbers

Source: Commissioning support units (CSU) dataset, January 2022

- The rate of GP referrals to PCS clinics is significantly higher for the age groups 35-49 (140 per 100,000) and 50-69 (157 per 100,000), compared to the Islington average (91 per 100,000).
- The rate of GP referrals to PCS clinics is significantly lower for the age groups 17-24 (34 per 100,000) compared to the Islington average.
- The higher referral rate in adults aged 35-69 aligns with the higher estimated prevalence and recorded prevalence in these age groups.

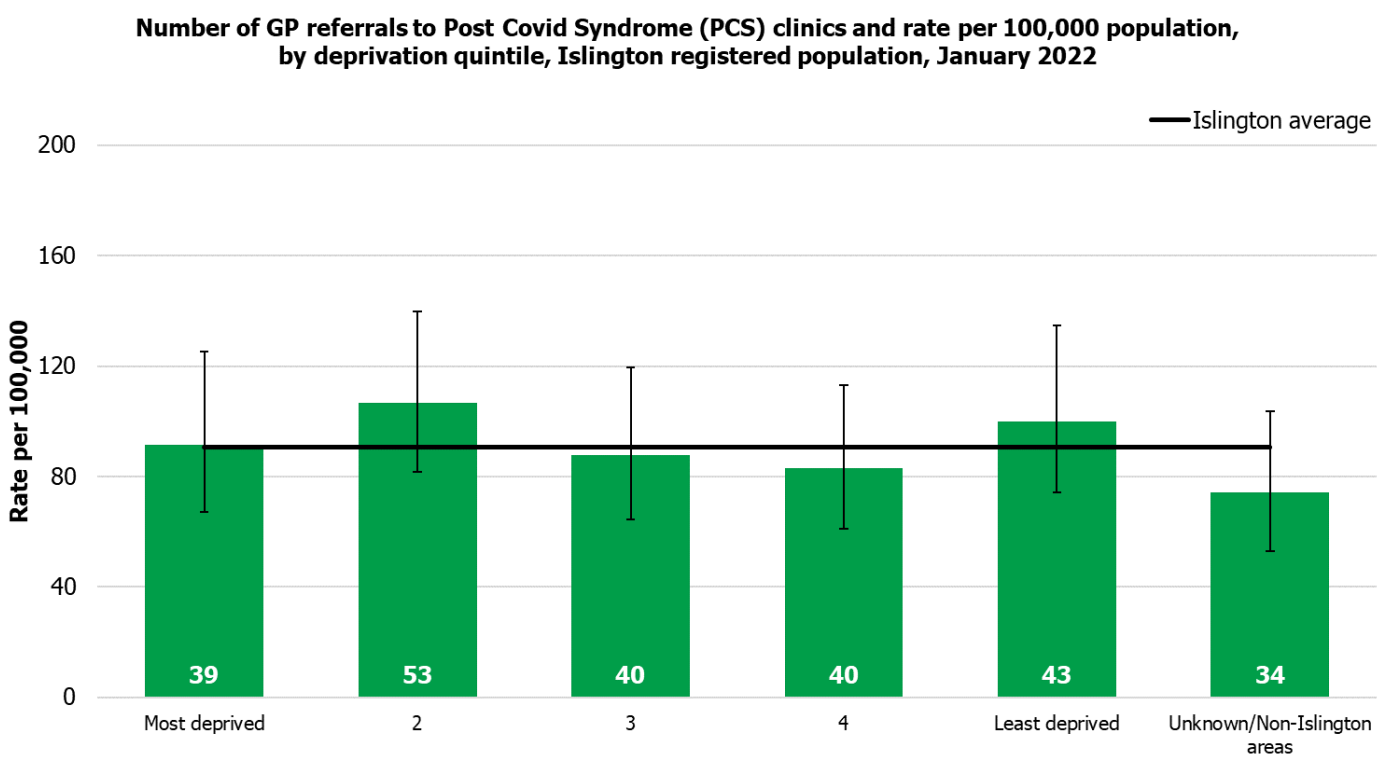
GP referrals, by ethnicity, Islington



- The rate of GP referrals to PCS clinics is significantly lower for Black ethnic groups (46 per 100,000), compared to the Islington average (91 per 100,000).

Source: Commissioning support units (CSU) dataset, January 2022

GP referrals, by deprivation, Islington

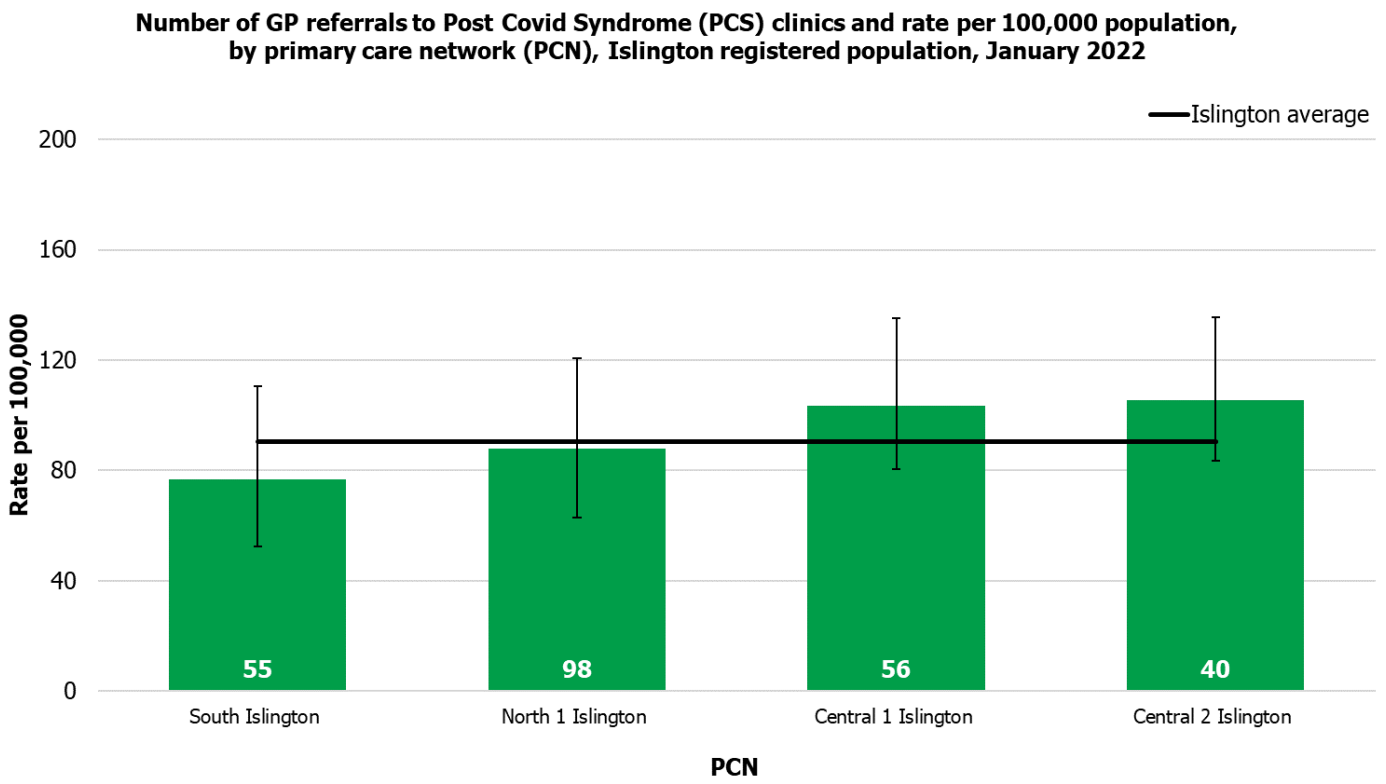


Note: Deprivation groupings based on IMD (2019) deciles, converted to quintiles as follows: Most deprived = 1, Second most deprived = 2, Third more deprived = 3, Second least deprived = 4 and Least deprived = 5.

Source: Commissioning support units (CSU) dataset, January 2022

- There are no significant differences in the rate of GP referrals to PCS Clinics between the most and least deprived areas in Islington.
- This contrasts to prevalence estimates that suggest higher prevalence in more deprived areas, but is in line with findings on recorded prevalence in Islington.

GP referrals, by primary care network (PCN), Islington



- There is variation in the rate of GP referrals to PCS Clinics between PCNs, though this is not statistically significant.

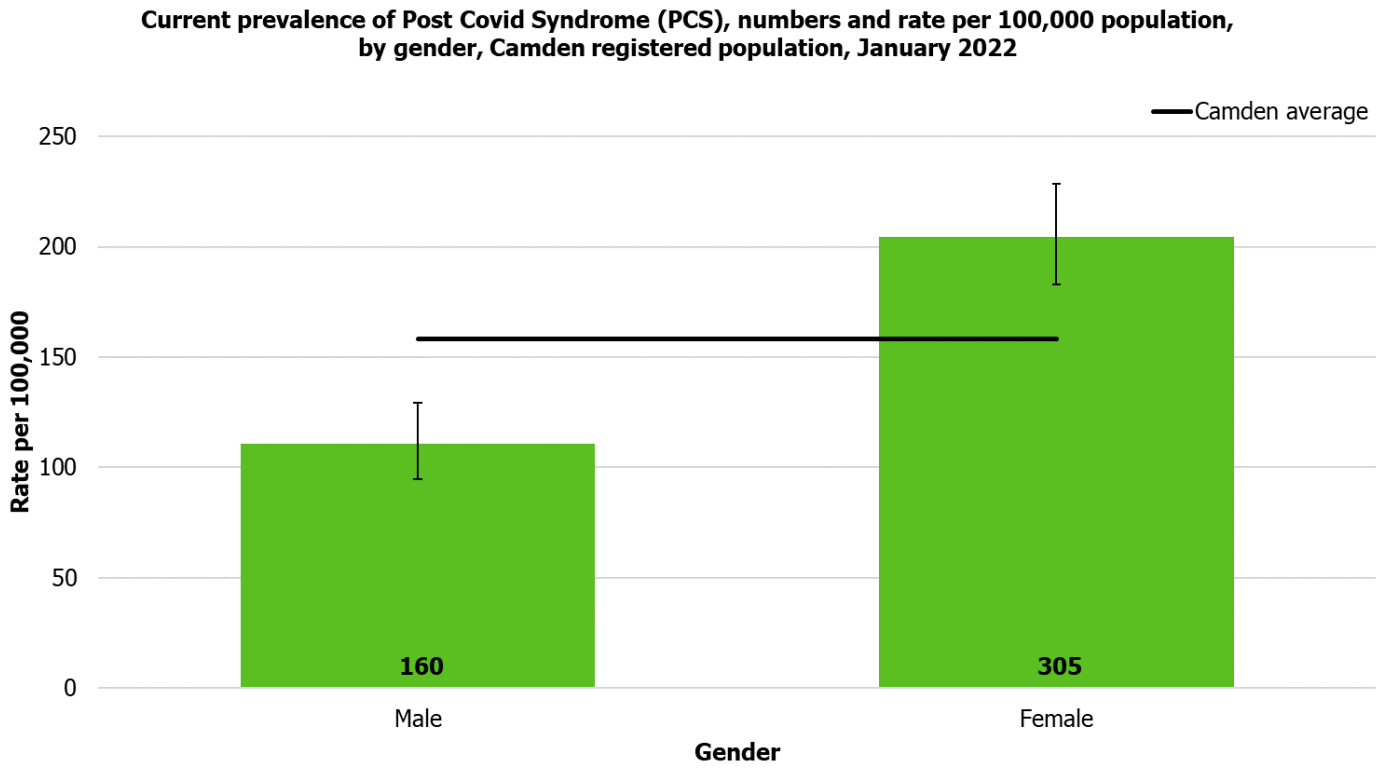
Source: Commissioning support units (CSU) dataset, January 2022

6. Borough Analysis: Camden

This section presents the overview of recorded prevalence of Post Covid Syndrome (PCS) and GP referrals to PCS clinics in Camden, by age, gender, ethnicity, deprivation and geographical level (primary care network [PCN]) where appropriate.

Data source: Commissioning support units (CSU) dataset, January 2022

Recorded prevalence, by gender, Camden

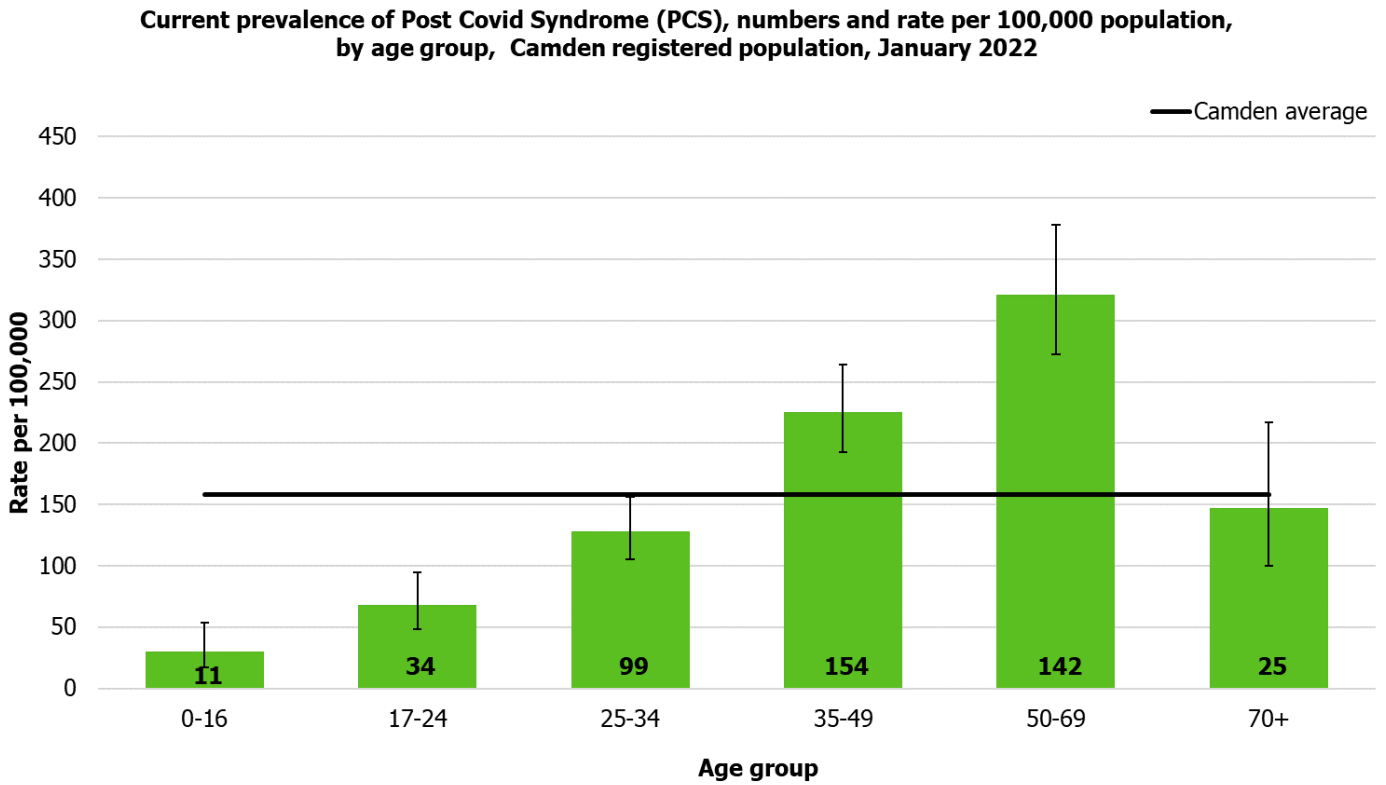


Note: 8 people recorded as having unknown gender have been excluded from this analysis

Source: Commissioning support units (CSU) dataset, January 2022

- The recorded prevalence of PCS is 158 per 100,000 registered population in Camden as of January 2022.
- The recorded prevalence among females (204 per 100,000) is almost double the prevalence for males (111 per 100,000).
- The association with gender aligns with prevalence estimates of higher prevalence in females.

Recorded prevalence, by age, Camden

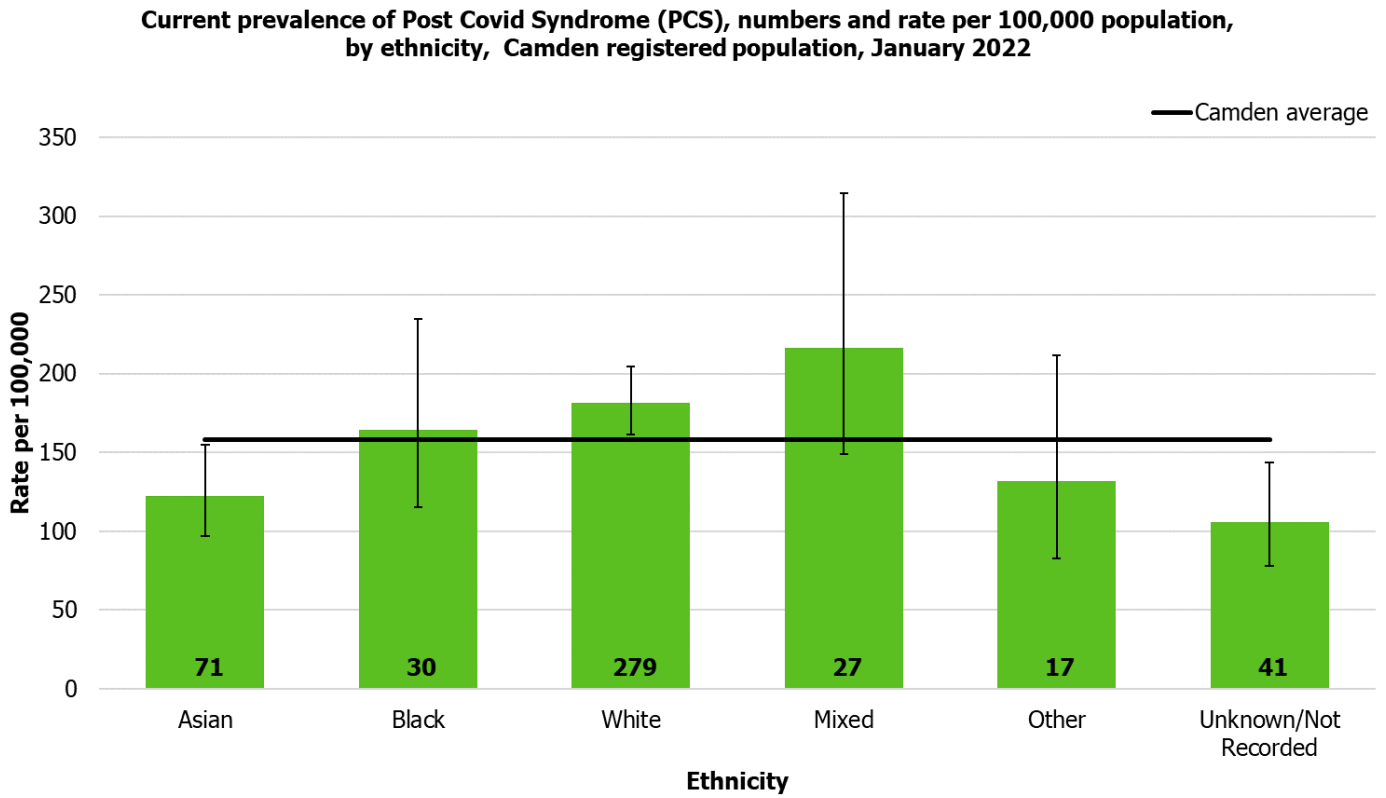


Note: Age group 0-16 has been grouped together due to small numbers

Source: Commissioning support units (CSU) dataset, January 2022

- The recorded prevalence of PCS is significantly higher among those aged 35 to 49 (225 per 100,000) and 50-69 (321 per 100,000), compared to the Camden average (158 per 100,000).
- The recorded prevalence of PCS is significantly lower among those aged 0-16 (30 per 100,000) and 17-24 (68 per 100,000) compared to the Camden average.
- The association with age aligns with prevalence estimates of higher prevalence in adults aged 35-69.

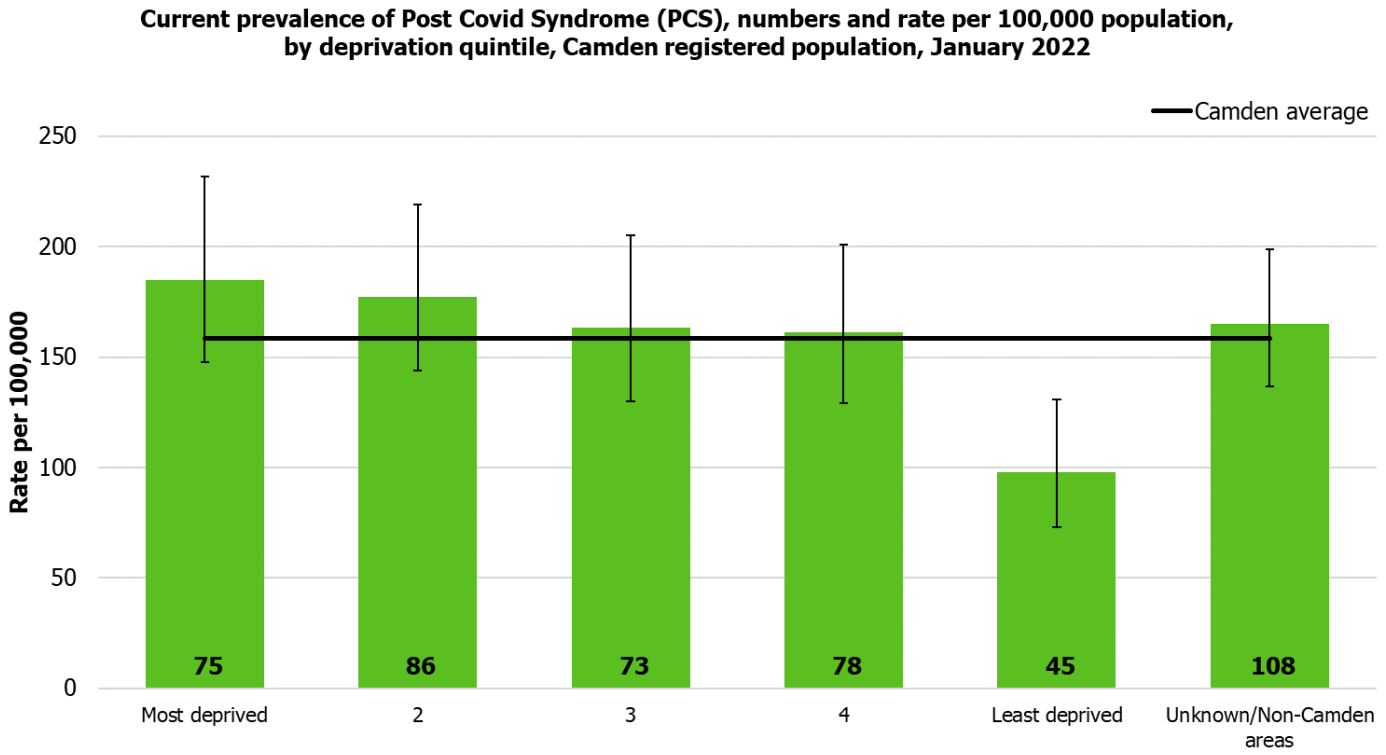
Recorded prevalence, by ethnicity, Camden



- The recorded prevalence of PCS is significantly higher among the White ethnic group (182 per 100,000), compared to the Camden average (158 per 100,000).
- The recorded prevalence of PCS is significantly lower among the Asian ethnic group (123 per 100,000) compared to the Camden average.
- **Note:** The ethnic category "White" does not specify whether this is White British or Other White.

Source: Commissioning support units (CSU) dataset, January 2022

Recorded prevalence, by deprivation, Camden

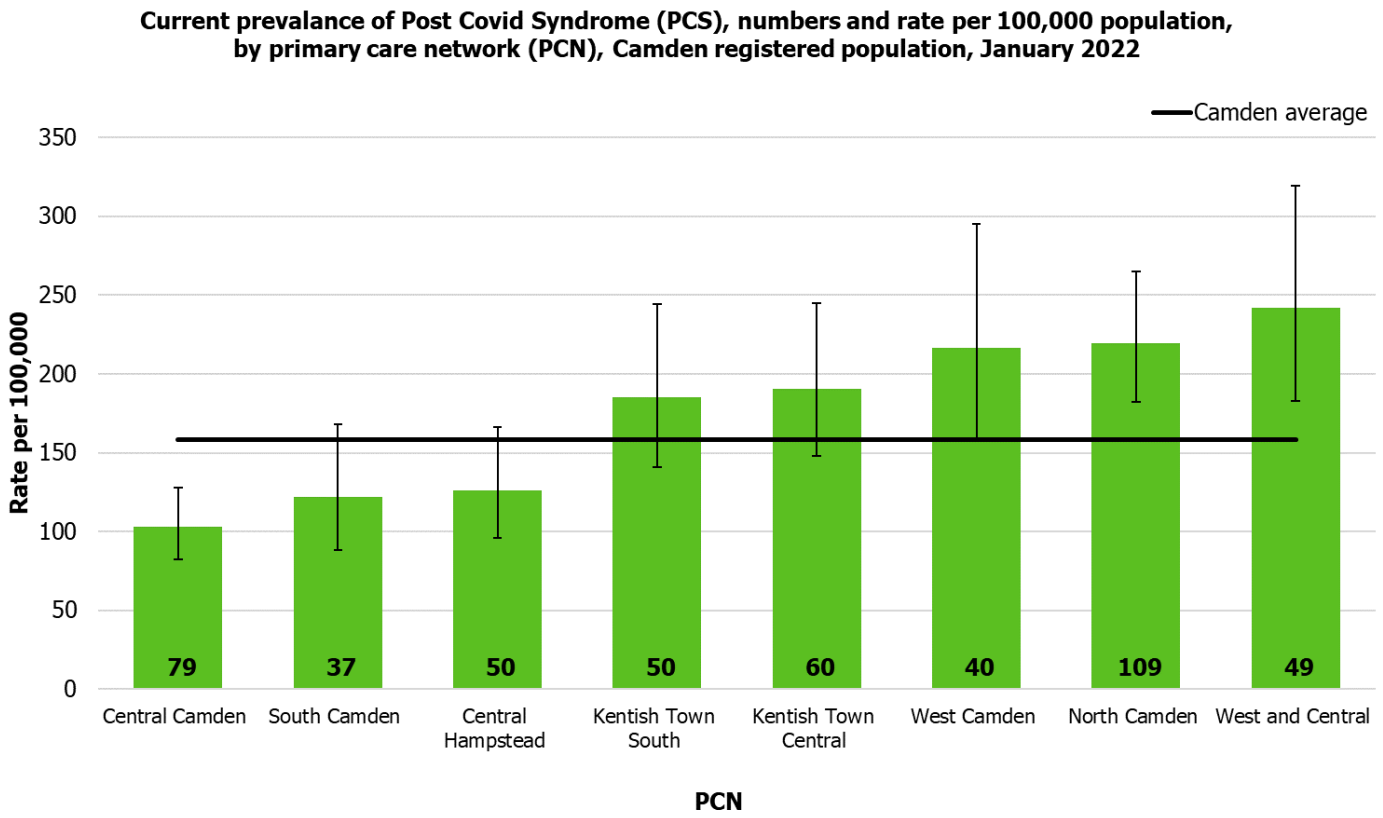


Note: Deprivation groupings based on IMD (2019) deciles, converted to quintiles as follows: Most deprived = 1, Second most deprived = 2, Third more deprived = 3, Second least deprived = 4 and Least deprived = 5.

Source: Commissioning support units (CSU) dataset, January 2022

- The least deprived areas in Camden have a significantly lower recorded prevalence of PCS (98 per 100,000) compared to the Camden average (158 per 100,000).
- The lower observed prevalence in the least deprived quintile aligns to an extent with prevalence estimates, though we would expect higher prevalence in the more deprived areas and the relationship is not clear.

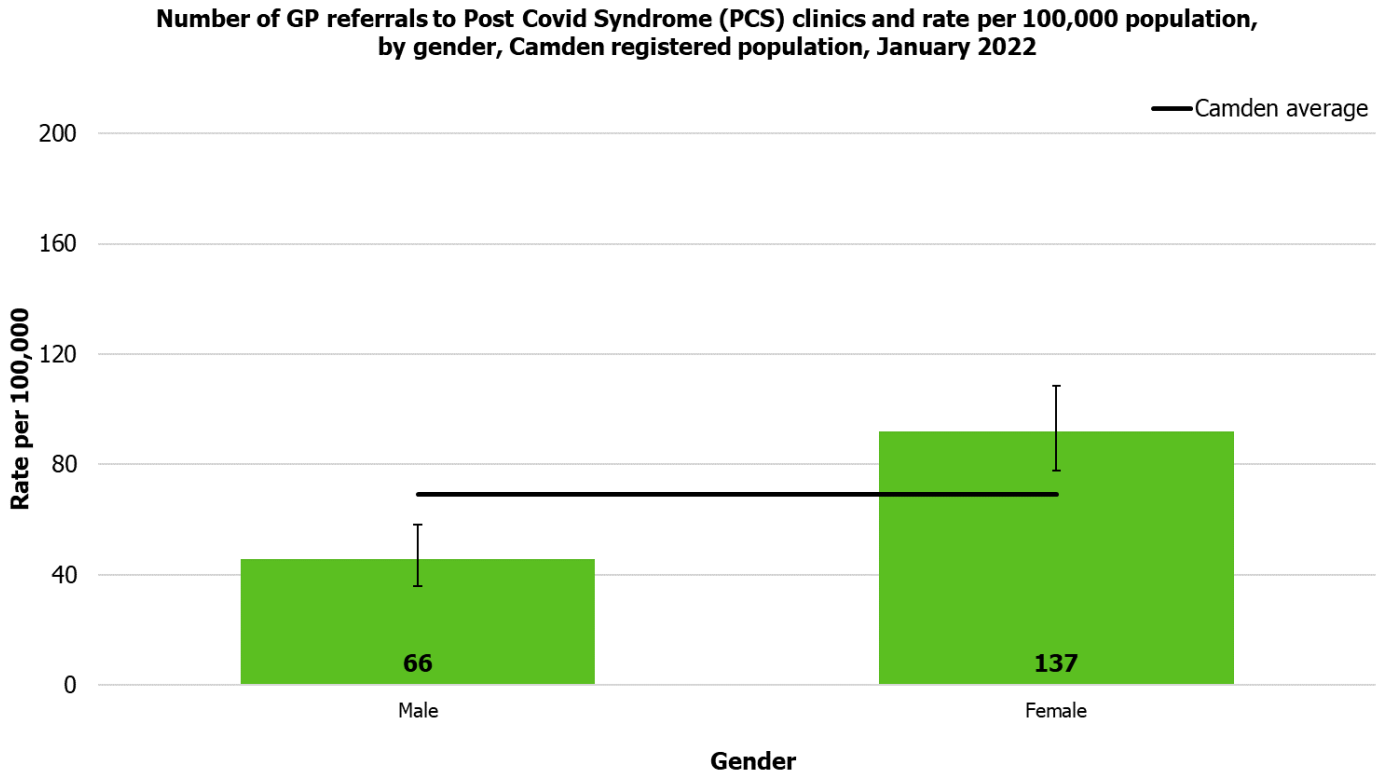
Recorded prevalence, by primary care network (PCN), Camden



Source: Commissioning support units (CSU) dataset, January 2022

- There is significant variation in recorded prevalence between Camden PCNs.
- West Camden PCN, North Camden PCN and West and Central PCN have a significantly higher prevalence (217, 220 and 242 per 100,000 respectively) compared to the Camden average (158 per 100,000).
- Central Camden PCN has a significantly lower prevalence of PCS (103 per 100,000) compared to the Camden average.

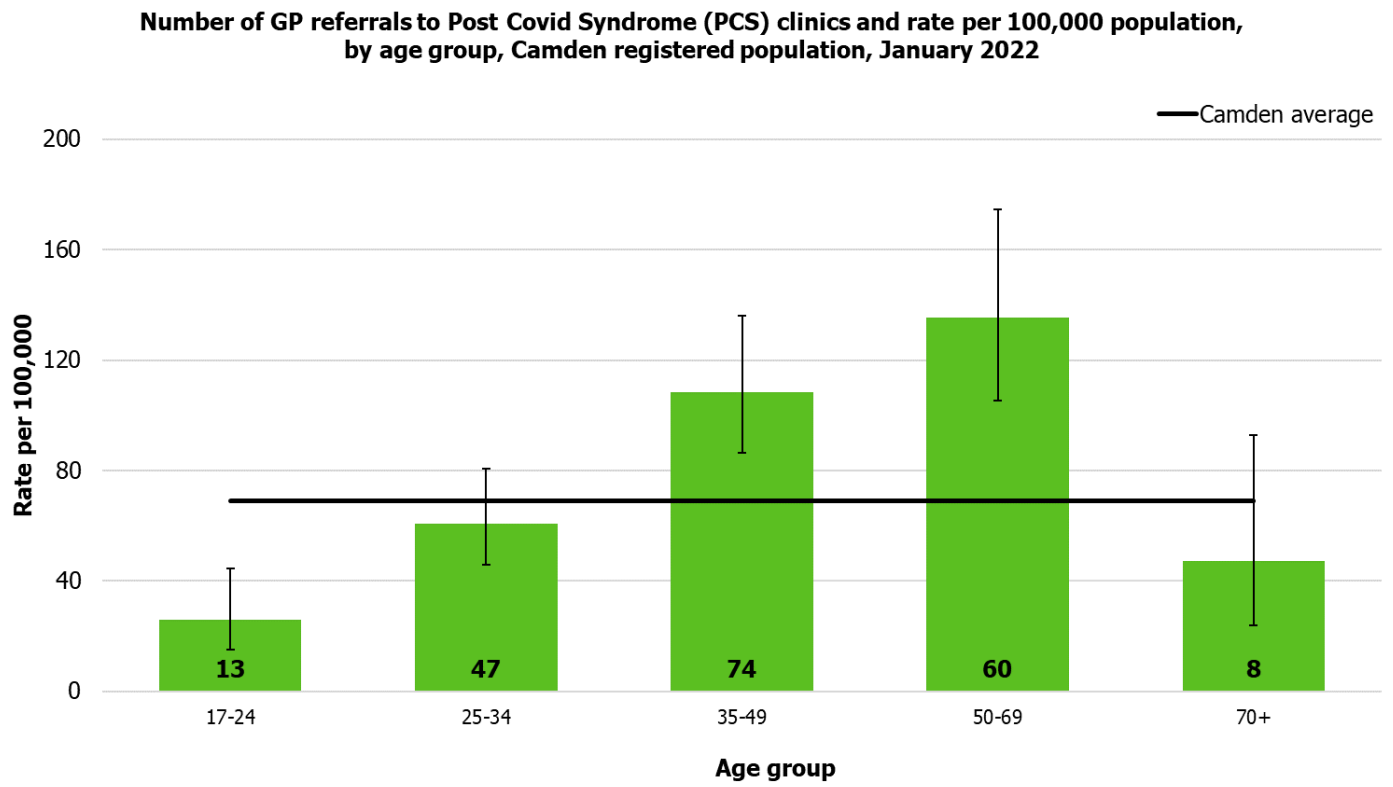
GP referrals, by gender, Camden



Note: 8 people recorded as having unknown gender have been excluded from this analysis
Source: Commissioning support units (CSU) dataset, January 2022

- The rate of GP referrals to PCS clinics is 69 per 100,000 registered population in Camden as of January 2022.
- The GP referral rates among females (92 per 100,000) is double compared to males (46 per 100,000).
- The higher referral rate in females aligns with the higher estimated prevalence and recorded prevalence in females.

GP referrals, by age, Camden

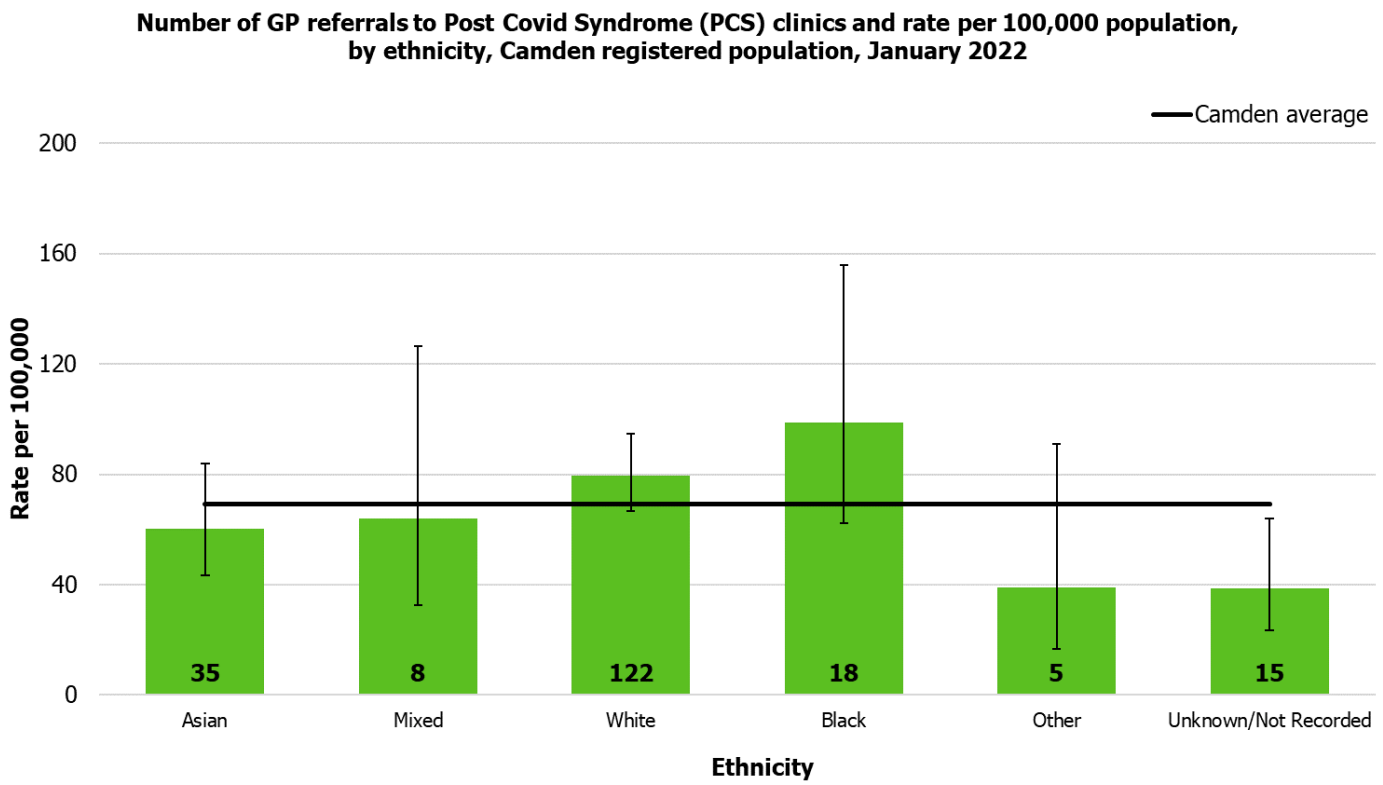


Note: Age group 0-16 has been excluded from this analysis due to small numbers

Source: Commissioning support units (CSU) dataset, January 2022

- GP referrals to PCS Clinics were significantly higher for the age group 35-49 (108 per 100,000) and 50-69 (136 per 100,000) compared to the Camden average (69 per 100,000).
- The rate of GP referrals to PCS clinics is significantly lower for the age groups 17-24 (26 per 100,000) compared to the Camden average.
- The higher referral rate in adults aged 35-69 adults aligns with the higher estimated prevalence and recorded prevalence in these age groups.

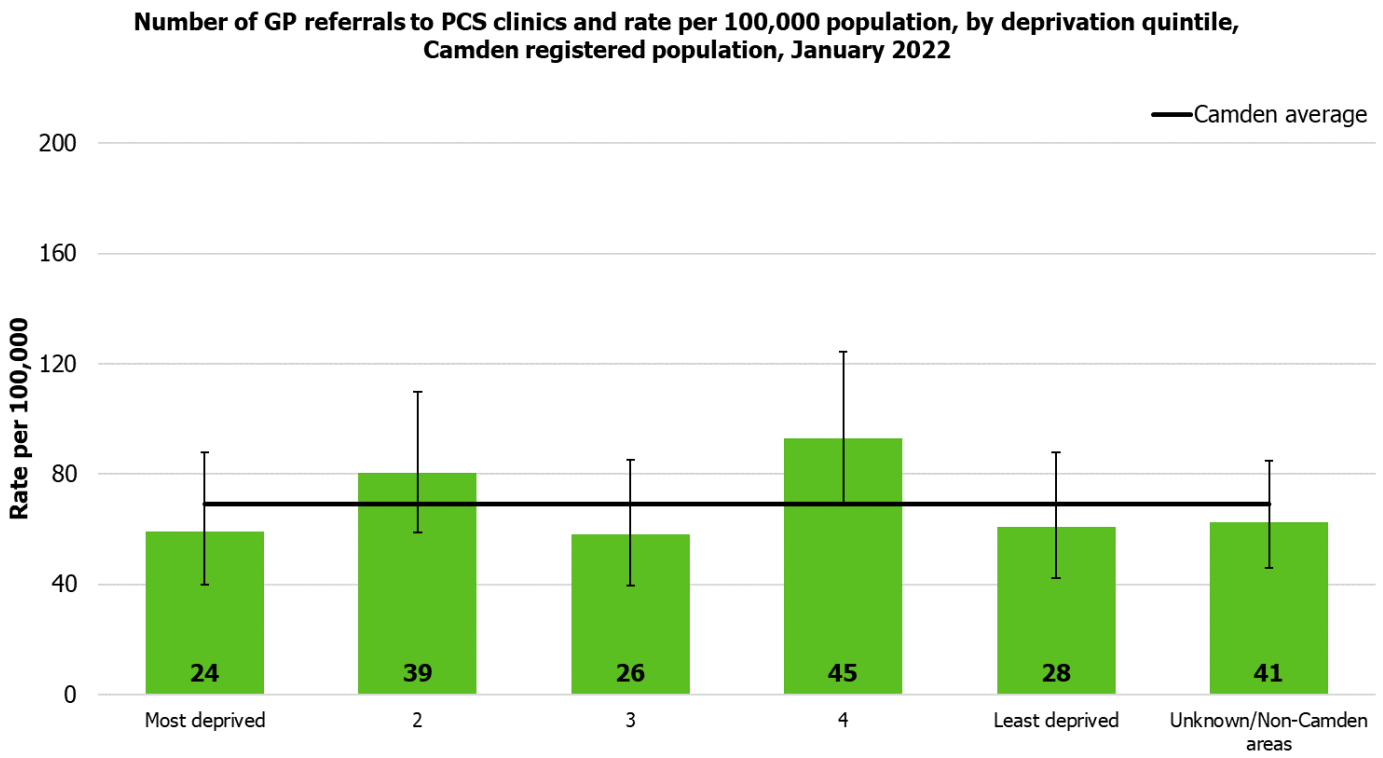
GP referrals, by ethnicity, Camden



Source: Commissioning support units (CSU) dataset, January 2022

- The rate of GP referrals to PCS clinics do not vary significantly with ethnicity.

GP referrals, by deprivation, Camden

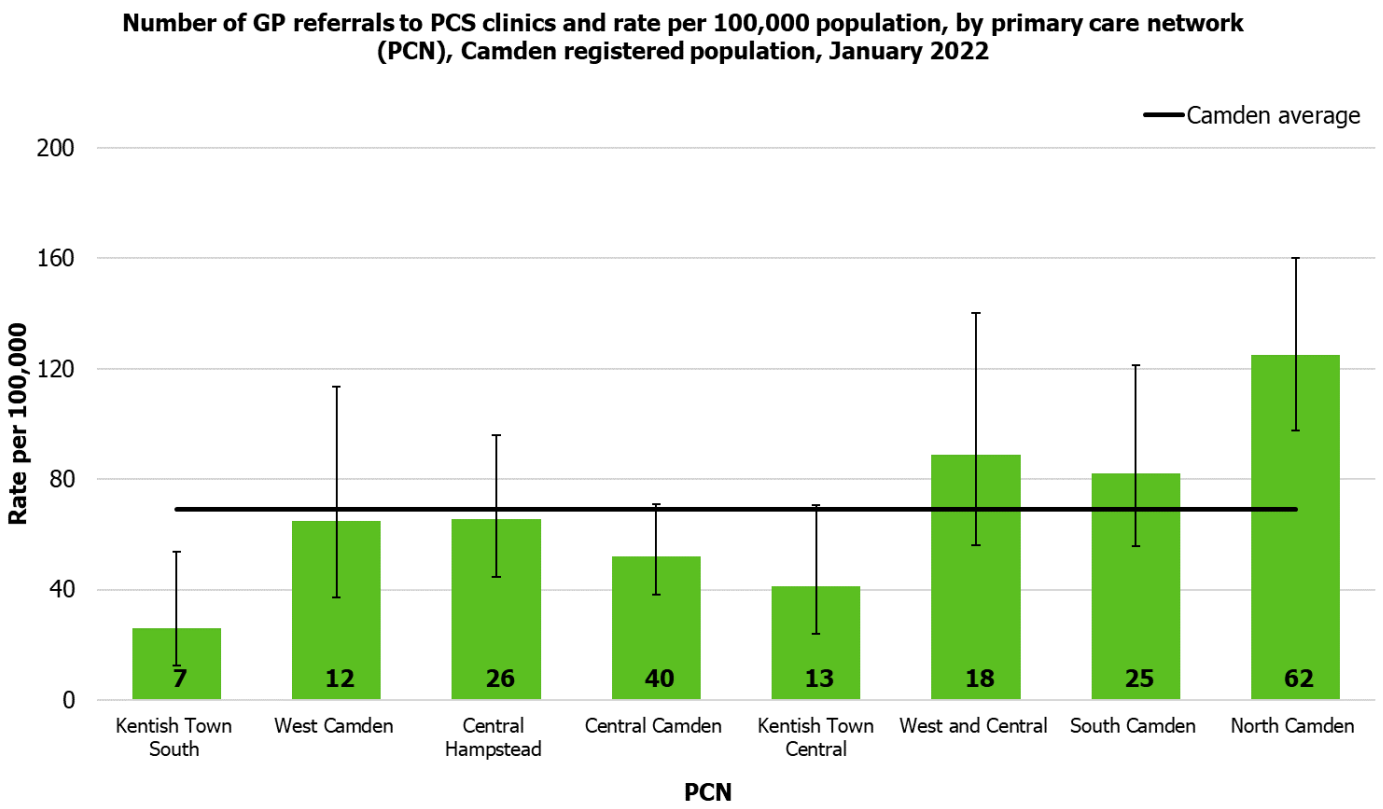


Note: Deprivation groupings based on IMD (2019) deciles, converted to quintiles as follows: Most deprived = 1, Second most deprived = 2, Third more deprived = 3, Second least deprived = 4 and Least deprived = 5.

Source: Commissioning support units (CSU) dataset, January 2022

- The second least deprived areas (Quintile 4) have significantly higher GP referrals to PCS clinics (93 per 100,000) compared to the Camden average (69 per 100,000).
- Overall there is no clear pattern in GP referrals by deprivation.

GP referrals, by primary care network (PCN), Camden



Source: Commissioning support units (CSU) dataset, January 2022

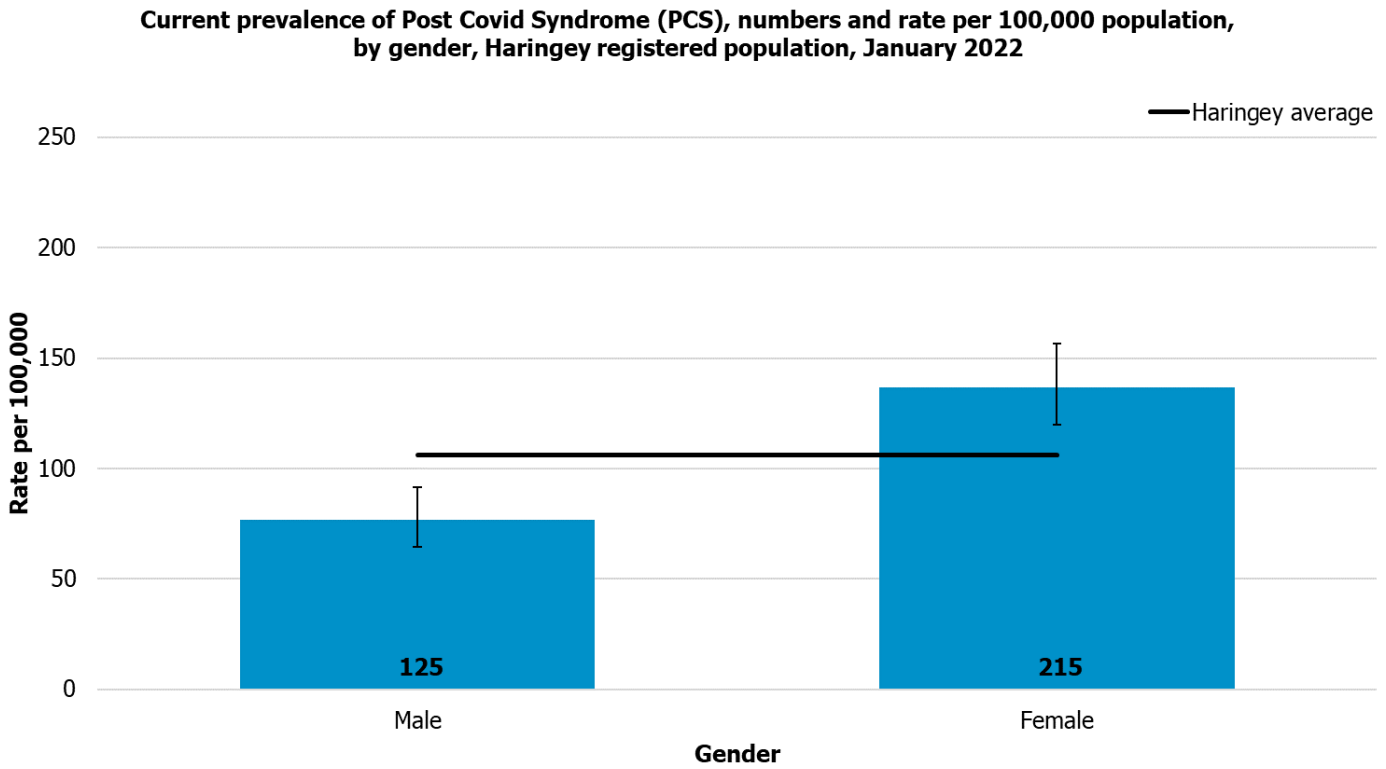
- North Camden PCN has a significantly higher GP referrals to PCS clinics (125 per 100,000) compared to the Camden Average (69 per 100,000).
- Kentish Town South PCN has a significantly lower GP referrals to PCS clinics (26 per 100,000) compared to the Camden Average.

7. Borough Analysis: Haringey

This section presents the overview of recorded prevalence of Post Covid Syndrome (PCS) and GP referrals to PCS clinics in Haringey, by age, gender, ethnicity, deprivation and geographical level (primary care network [PCN]) where appropriate.

Data source: Commissioning support units (CSU) dataset, January 2022

Recorded prevalence, by gender, Haringey

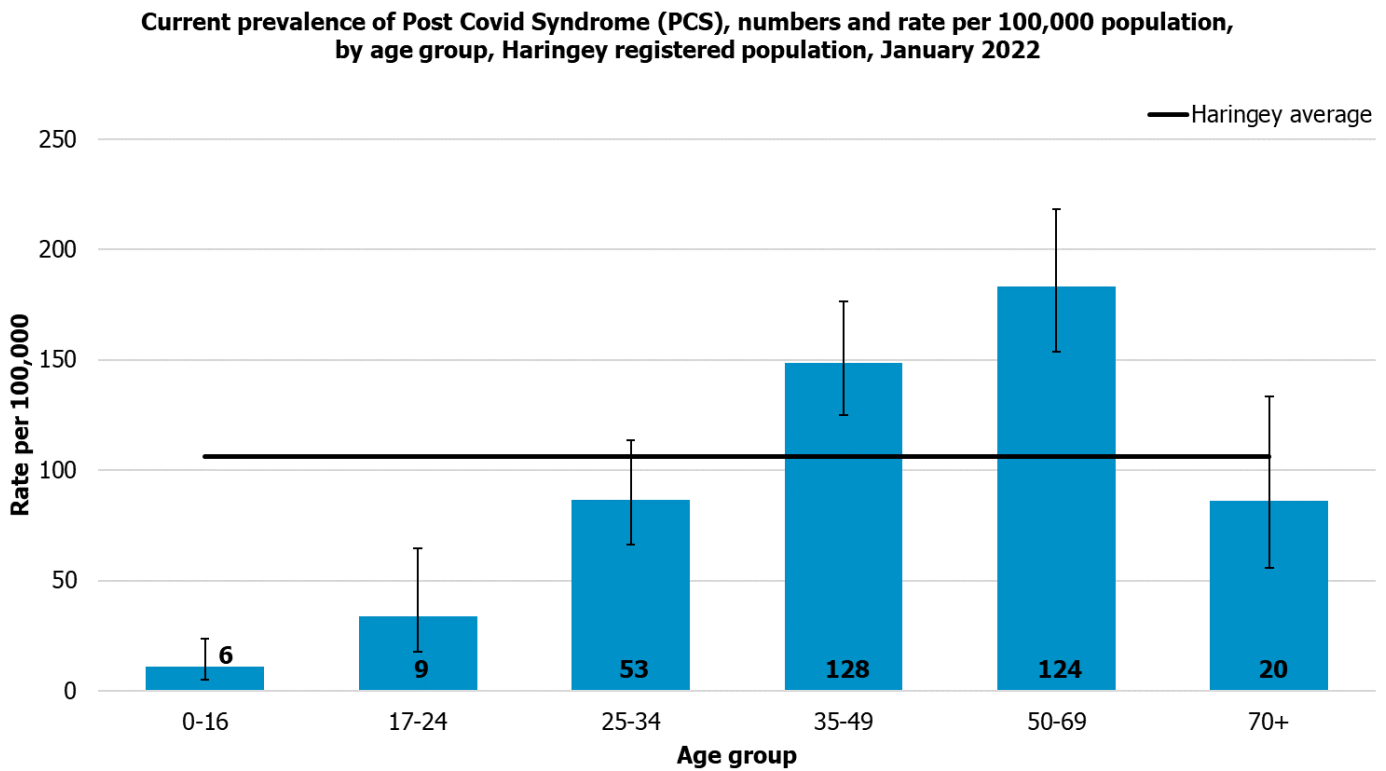


Note: 15 people recorded as having unknown gender have been excluded from this analysis

Source: Commissioning support units (CSU) dataset, January 2022

- The recorded prevalence of PCS is 106 per 100,000 registered population in Haringey as of January 2022.
- The recorded prevalence among females (137 per 100,000) is almost double the prevalence for males (77 per 100,000).
- The association with gender aligns with prevalence estimates of higher prevalence in females.

Recorded prevalence, by age, Haringey

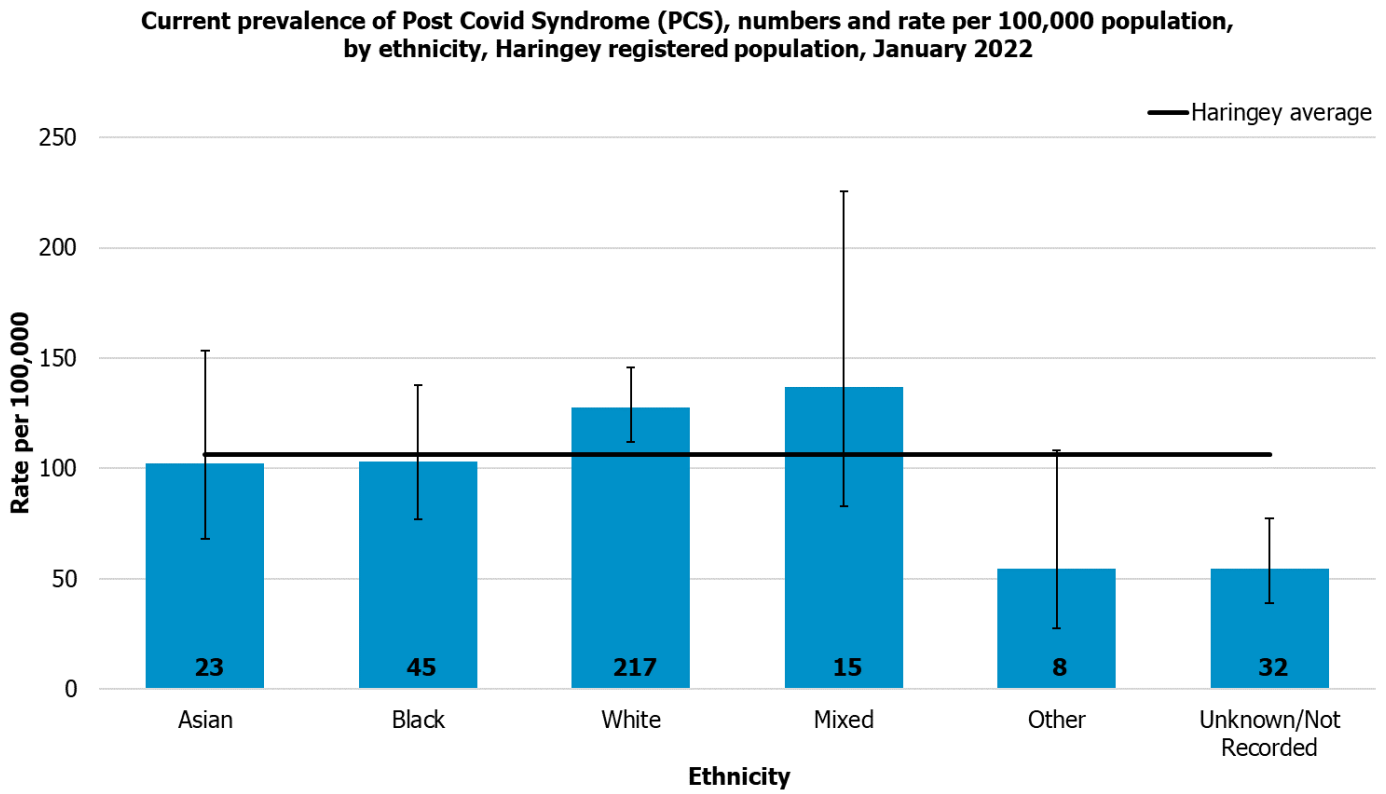


Note: Age group 0-16 has been grouped together due to small numbers

Source: Commissioning support units (CSU) dataset, January 2022

- The recorded prevalence of PCS is significantly higher among those aged 35 to 49 (149 per 100,000) and 50-69 (183 per 100,000), compared to the Haringey average (106 per 100,000).
- The recorded prevalence of PCS is significantly lower among those aged 0 to 16 (11 per 100,000) and 17 to 24 (34 per 100,000), compared to the Haringey average.
- The association with age aligns with prevalence estimates that suggest higher prevalence in adults aged 35-69.

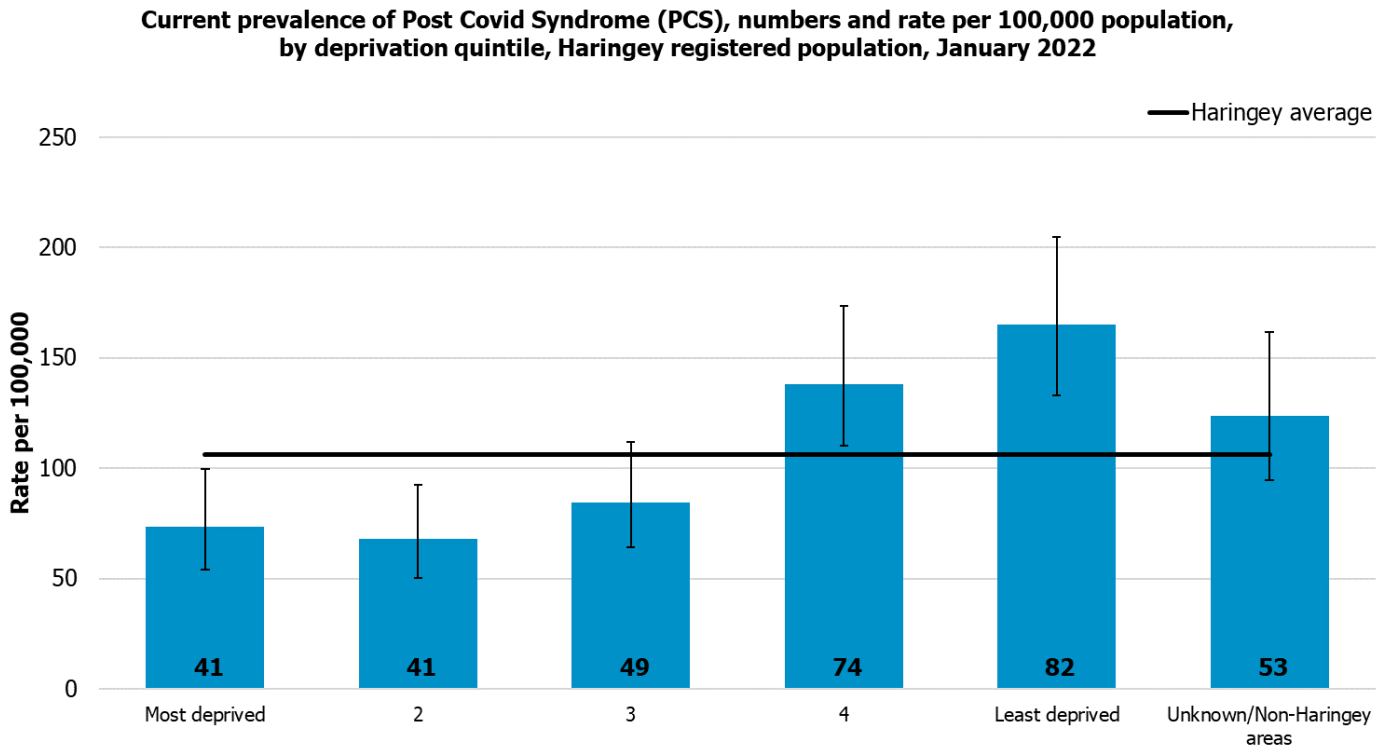
Recorded prevalence, by ethnicity, Haringey



- The recorded prevalence of PCS is significantly higher among the White ethnic group (128 per 100,000), compared to the Haringey average (106 per 100,000).

Source: Commissioning support units (CSU) dataset, January 2022

Recorded prevalence, by deprivation, Haringey

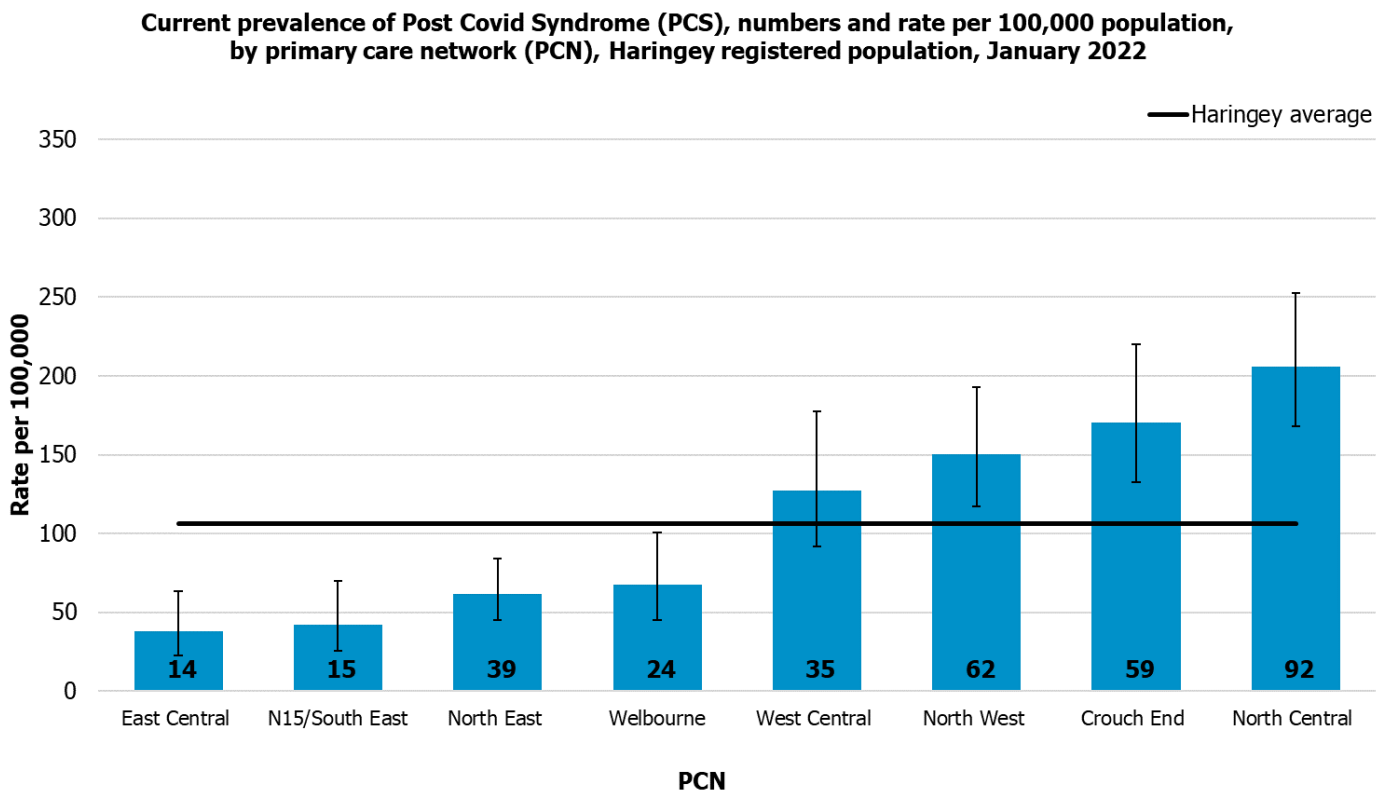


Note: Deprivation groupings based on IMD (2019) deciles, converted to quintiles as follows: Most deprived = 1, Second most deprived = 2, Third more deprived = 3, Second least deprived = 4 and Least deprived = 5.

Source: Commissioning support units (CSU) dataset, January 2022

- The most deprived areas have significantly lower recorded prevalence (68-73 per 100,000) while the least deprived areas have significantly higher recorded prevalence of PCS (138-165 per 100,000) compared to the Haringey average (106 per 100,000).
- This is in stark contrast with prevalence estimates that suggests we would expect to see higher prevalence in more deprived areas.

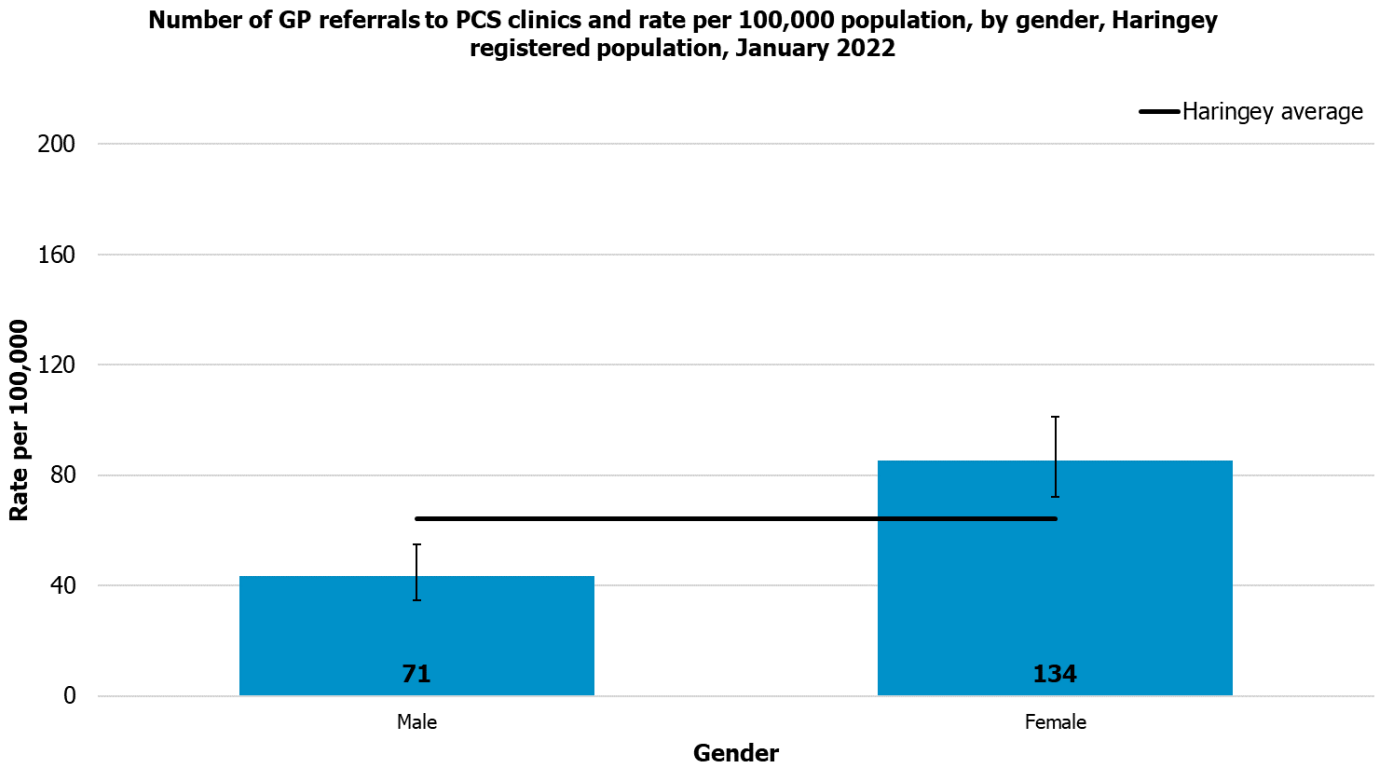
Recorded prevalence, by primary care network (PCN), Haringey



Source: Commissioning support units (CSU) dataset, January 2022

- There is significant variation in recorded prevalence between PCNs in Haringey.
- North West PCN, Crouch End PCN and North Central PCN have significantly higher recorded prevalence of PCS (151, 171 and 206 per 100,000 respectively), compared to the Haringey average (106 per 100,000).
- East Central PCN, N15/South East PCN, North East PCN and Welbourne PCN have a significantly lower recorded prevalence of PCS (38-68 per 100,000) compared to the Haringey average.

GP referrals, by gender, Haringey

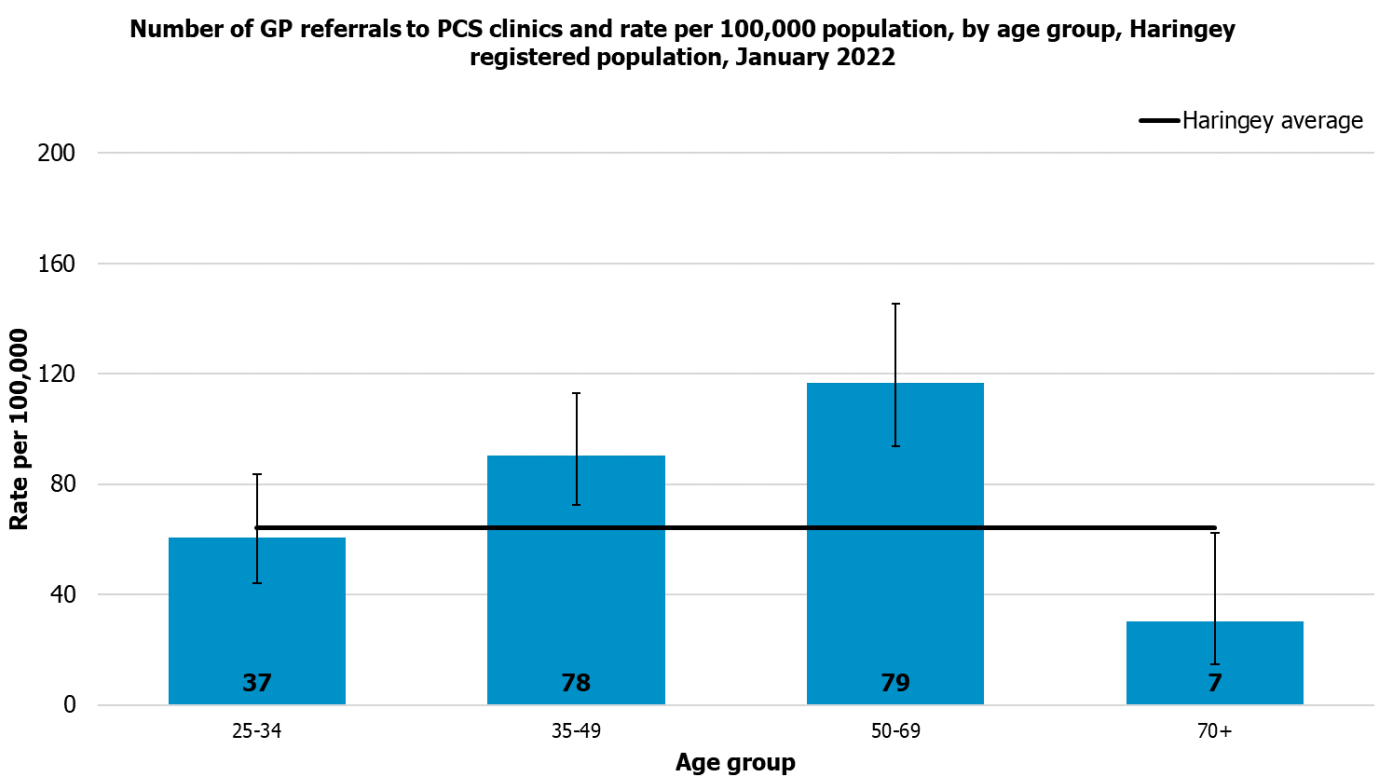


Note: 15 people recorded as having unknown gender have been excluded from this analysis

Source: Commissioning support units (CSU) dataset, January 2022

- The rate of GP referrals to PCS clinics is 64 per 100,000 registered population in Haringey as of January 2022.
- The GP referral rates among females (85 per 100,000) is double compared to males (44 per 100,000).
- The higher referral rate in females aligns with the higher estimated prevalence and recorded prevalence in females.

GP referrals, by age, Haringey

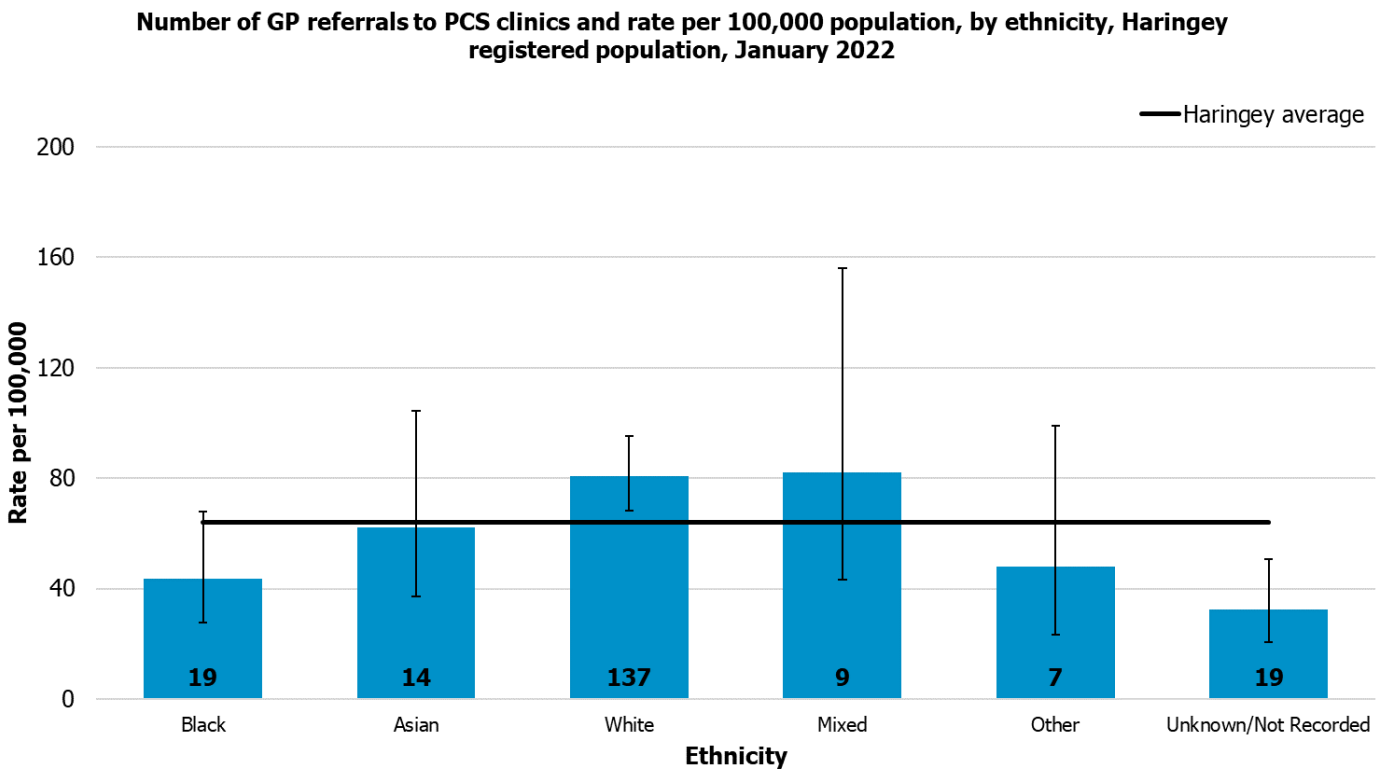


Note: Age group 0-24 has been excluded from this analysis due to small numbers

Source: Commissioning support units (CSU) dataset, January 2022

- GP referrals to PCS Clinics were significantly higher for the age group 35-49 (91 per 100,000) and 50-69 (117 per 100,000) compared to the Haringey average (64 per 100,000).
- GP referrals to PCS Clinics were significantly lower for the age group 70+ (30 per 100,000) compared to the Haringey average.
- The higher referral rate in adults aged 35-69 aligns with the higher estimated prevalence and recorded prevalence in this age group.

GP referrals, by ethnicity, Haringey

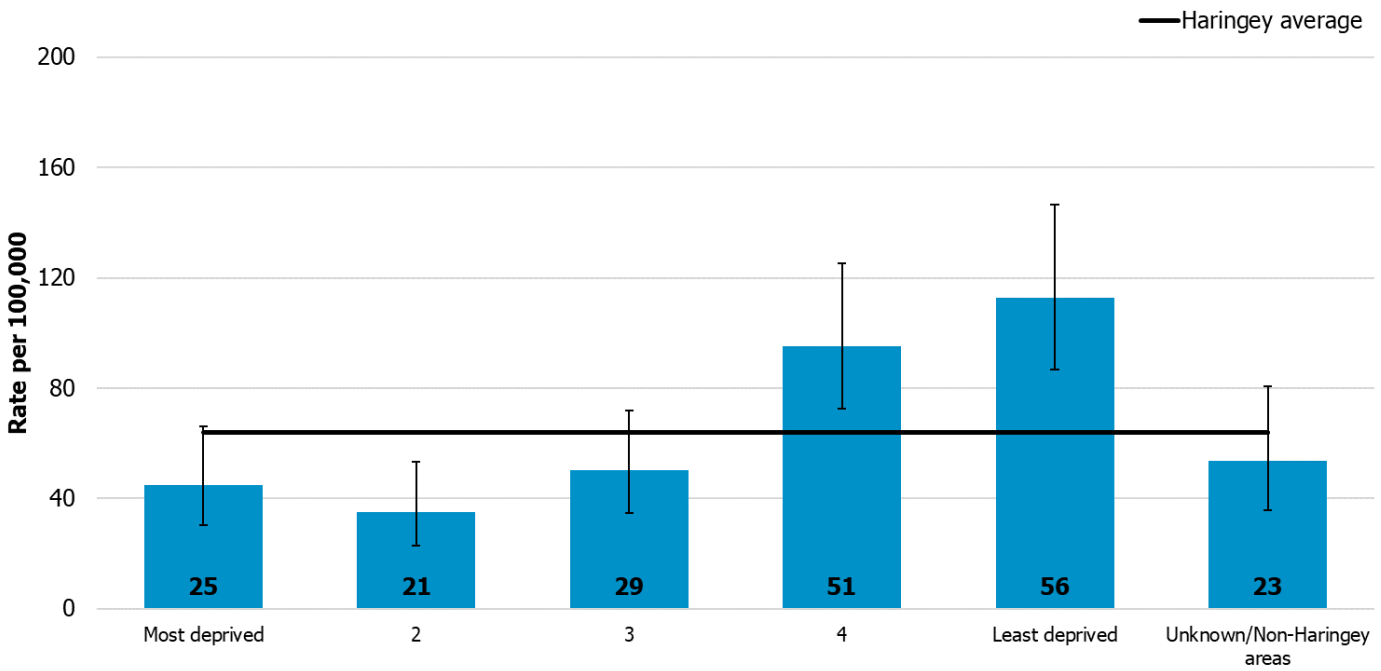


Source: Commissioning support units (CSU) dataset, January 2022

- The White ethnic group have significantly higher rate of GP referrals to PCS Clinics (81 per 100,000), compared to the Haringey average (64 per 100,000).
- For those with no recorded ethnicity the referral rate was significantly lower (32 per 100,000) compared to the Haringey average.

GP referrals, by deprivation, Haringey

Number of GP referrals to PCS clinics and rate per 100,000 population, by deprivation quintile, Haringey registered population, January 2022

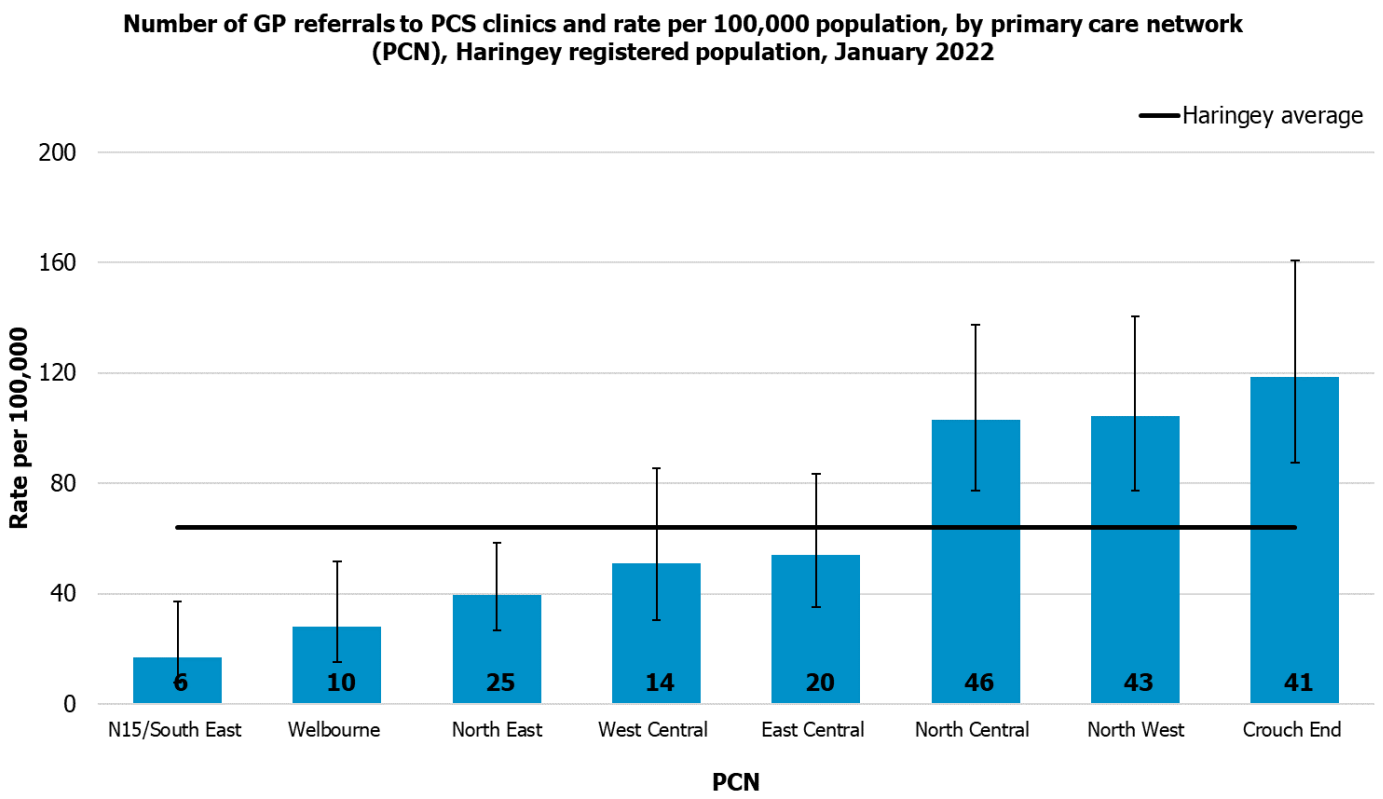


Note: Deprivation groupings based on IMD (2019) deciles, converted to quintiles as follows: Most deprived = 1, Second most deprived = 2, Third more deprived = 3, Second least deprived = 4 and Least deprived = 5.

Source: Commissioning support units (CSU) dataset, January 2022

- The two least deprived areas have significantly higher GP referrals to PCS Clinics (95-113 per 100,000), compared to the Haringey average (64 per 100,000).
- The second most deprived areas have significantly lower referral rate (35 per 100,000), compared to the Haringey average.
- This is in contrast with estimated prevalence that suggest higher prevalence in more deprived areas, but is in line with the recorded prevalence in Haringey.

GP referrals, by primary care network (PCN), Haringey



Source: Commissioning support units (CSU) dataset, January 2022

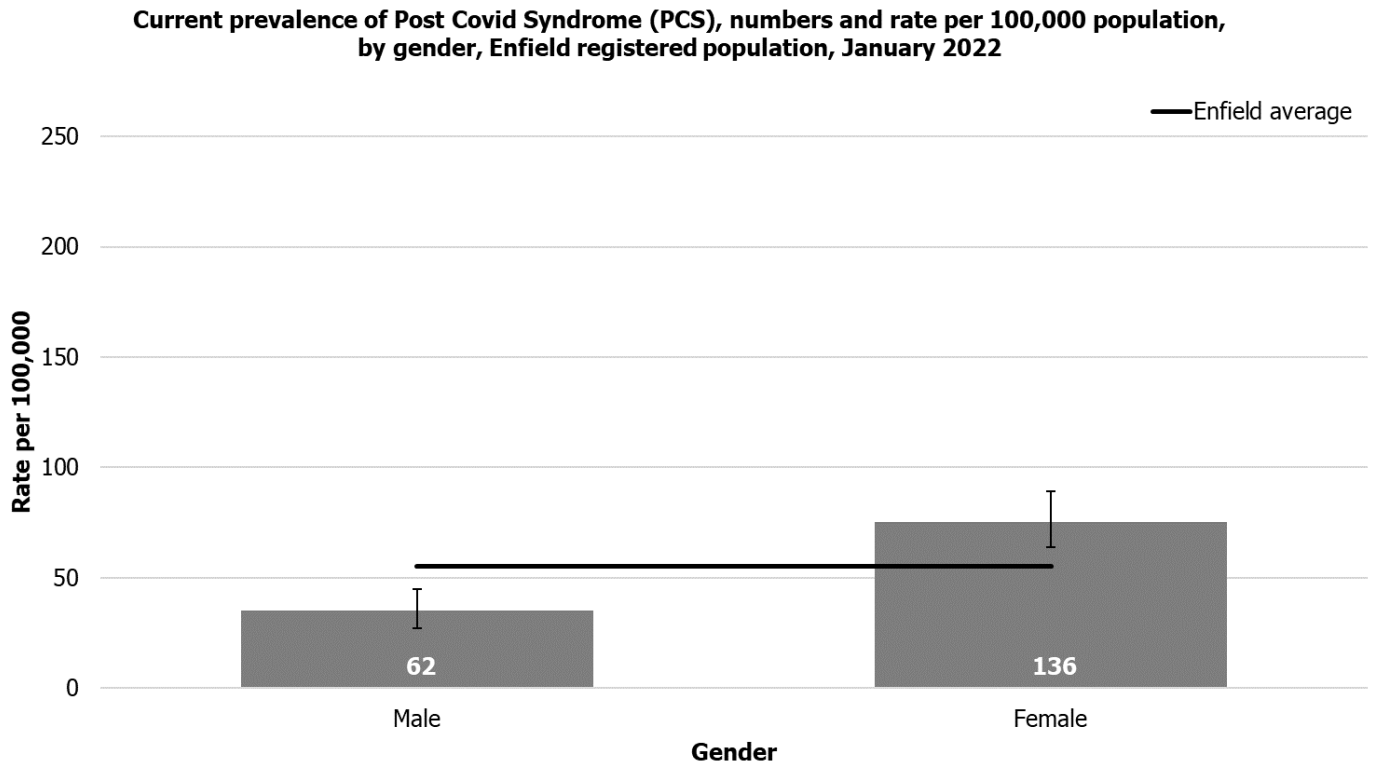
- There is significant variation in GP referral rates between Haringey PCNs.
- North Central PCN, North West PCN and Crouch End PCN have a significantly higher rate of GP referrals to PCS clinics (103, 104 and 119 per 100,000 respectively), compared to the Haringey average (64 per 100,000).
- N15/South East PCN, Welbourne PCN and North East PCN have a significantly lower rate of referrals (17-40 per 100,000), compared to the Haringey average.

8. Borough Analysis: Enfield

This section presents the overview of recorded prevalence of Post Covid Syndrome (PCS) and GP referrals to PCS clinics in Enfield, by gender and geographical level (primary care network [PCN]) where appropriate.

Data source: Commissioning support units (CSU) dataset, May 2021

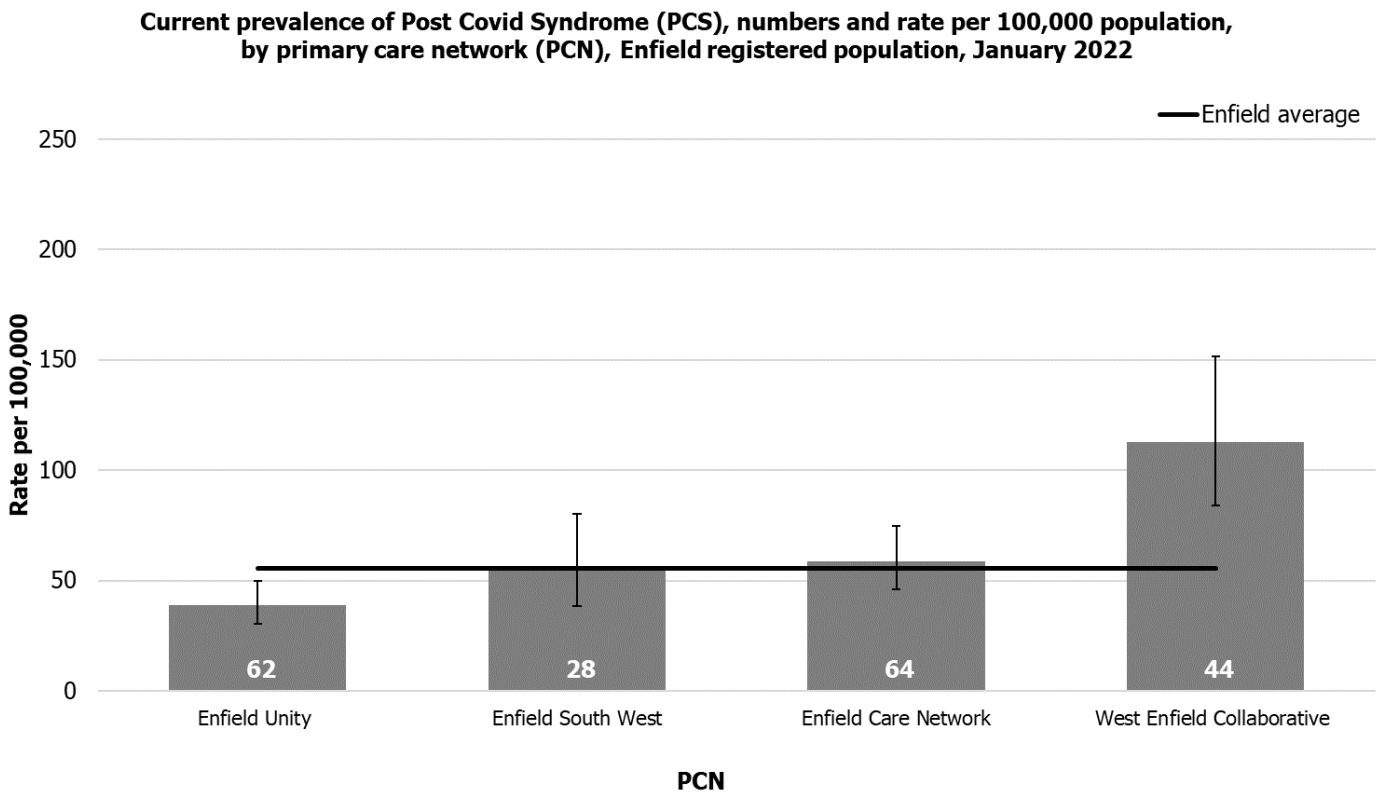
Recorded prevalence, by gender, Enfield



Source: Commissioning support units (CSU) dataset, January 2022

- The recorded prevalence of PCS is 55 per 100,000 registered population in Enfield as of January 2022.
- The recorded prevalence among females (75 per 100,000) is almost double compared to males (35 per 100,000).
- The association with gender aligns with prevalence estimates that suggest higher prevalence in females.

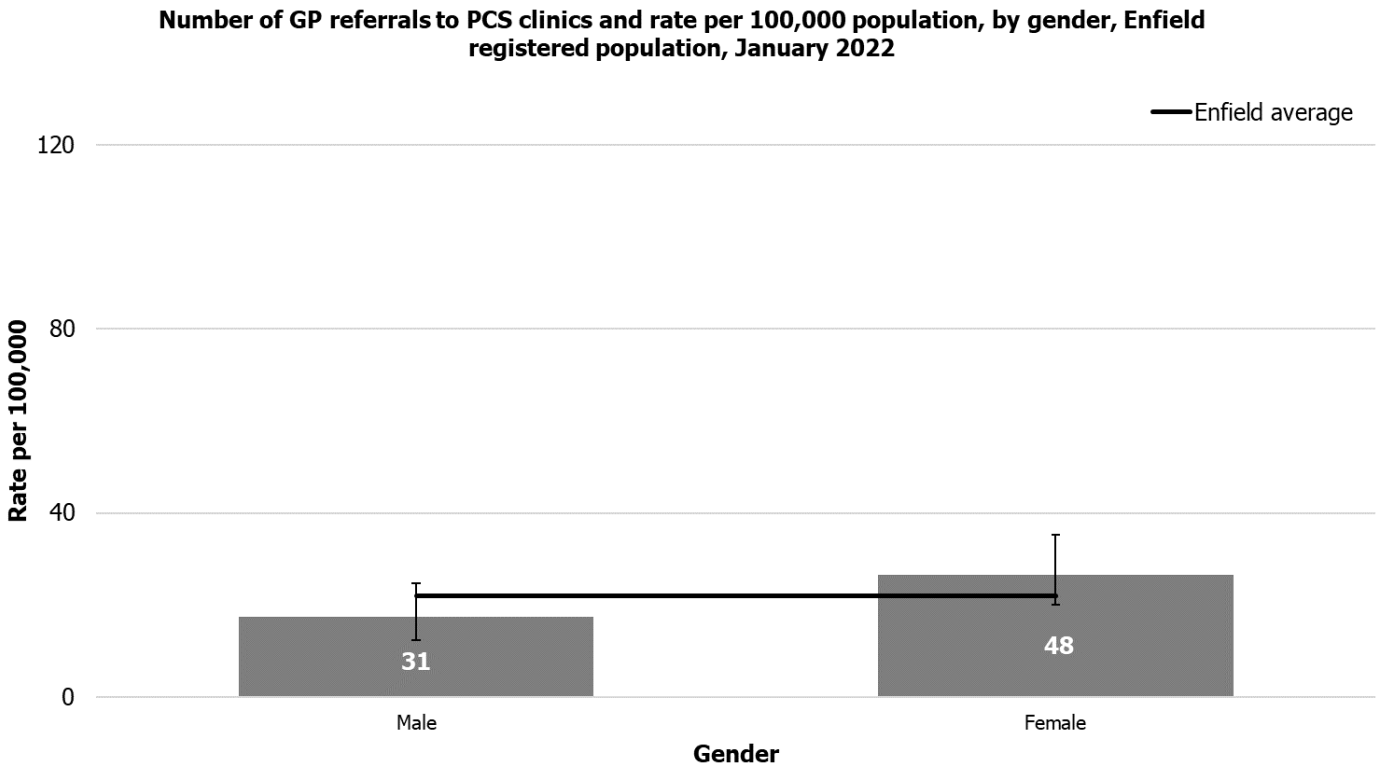
Recorded prevalence, by primary care network (PCN), Enfield



Source: Commissioning support units (CSU) dataset, January 2022

- West Enfield Collaborative PCN has a significantly higher prevalence of PCS (113 per 100,000) compared to the Enfield average (55 per 100,000).
- Enfield Unity PCN has a significantly lower prevalence of PCS (39 per 100,000) compared to the Enfield average.

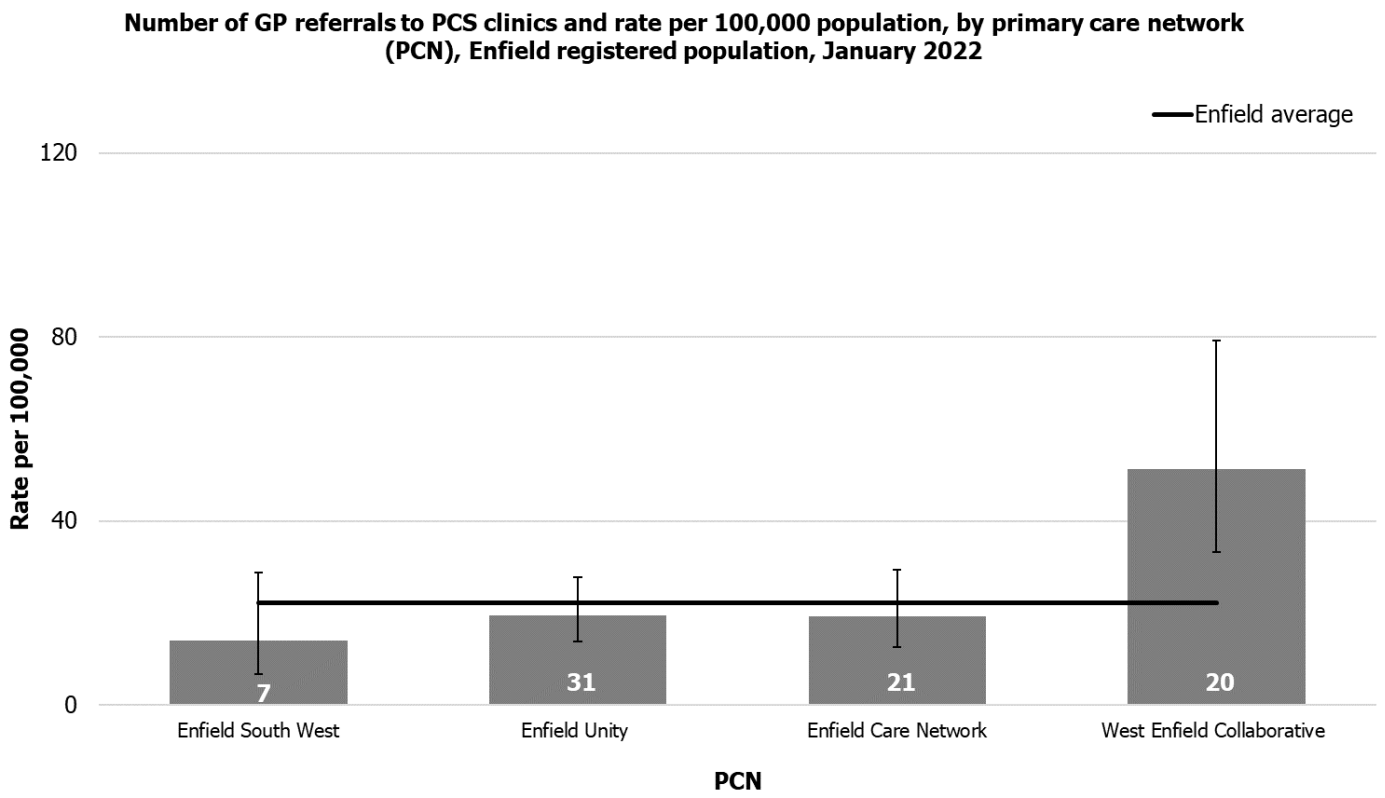
GP referrals, by gender, Enfield



Source: Commissioning support units (CSU) dataset, January 2022

- The rate of GP referrals to PCS clinics is 22 per 100,000 registered population in Enfield as of January 2022.
- There is no significant differences in referral rates among males and females compared to the Enfield average.

GP referrals, by primary care network (PCN), Enfield



Source: Commissioning support units (CSU) dataset, January 2022

- West Enfield Collaborative PCN has a significantly higher GP referrals to PCS clinics (51 per 100,000) compared to the Enfield average (22 per 100,000).
- The rate of referrals across Enfield PCNs ranges from 14 to 51 per 100,000.

9. Summary

This section presents a summary of the main findings of this needs assessment

Summary

1. Estimated/expected prevalence of Post-Covid Syndrome in NCL boroughs (using ONS estimates) **is far higher than observed prevalence** from recorded diagnoses (slide 18).

This may be due to numerous reasons, such as:

- **Lack of awareness of Long COVID:** In the Healthwatch report, 34% did not know they were experiencing Long COVID, so more work is needed to raise awareness of the condition and trusted information sources, and to encourage people to seek a formal diagnosis.
- **Lack of awareness of avenues of support:** In the Healthwatch report, 51% had not sought a diagnosis because they did not think their GP could help. More work is needed to raise awareness of the NCL pathway, and avenues of support and services available locally and online.
- **Inconsistent diagnostic or coding practices**: Some patients with Post-Covid symptoms may not have been coded as such following presentation to their GP. Diagnosis remains a challenge, and there is variation in diagnostic rates between PCNs. Work is needed to improve consistency in diagnostic practice.

Summary

2. Rates of diagnosis and referral:

- Breakdown by **age and gender** generally align with prevalence estimates, with higher rates of diagnosis and referrals observed in women and working age adults.
- Breakdown by **deprivation and ethnicity** are less clear. National estimates suggest we would expect higher prevalence in more deprived areas, though this is not always the case. In Haringey for example, recorded diagnoses and referrals are higher in less deprived areas.
- There is **variation** in diagnosis and referral rates by Primary Care Network (PCN), and more action is needed to reduce unwarranted variation.

3. Specialist Clinic:

- The majority of patients are waiting >14 weeks between referral and assessment in the specialist clinic.
- Breakdown by age and gender aligns with prevalence estimates. There is low recording of ethnicity data in the service, and so improved recording would enable a better understanding of service use variation by ethnicity
- The most common onward referral is for rehabilitation, most commonly for fatigue management.

Summary

4. Future outlook:

- Waves of Covid-19 infection will continue to occur as we 'learn to live with the virus' and it becomes endemic in the UK.
- Despite on average, milder acute Covid-19 illness at the present time compared to the start of the pandemic (due to the impact of variants, the vaccination programme, and natural immunity), new cases of Post-covid syndrome are continuing to occur (slide 10).
- Also, there remains a high proportion of individuals who have suffered from Post-covid syndrome for over a year (slide 10), including some for over 2 years, and these individuals will have a continued need for services and support, particularly since effective medical therapeutics are yet to be developed.
- It is therefore clear that there will be a continued need for Post-Covid services going forwards, and so efforts should continue around raising awareness, improving diagnosis and the effectiveness of the NCL pathway, and implementing the recommendations of the Healthwatch report* to improve patients' experiences.

*Healthwatch: People's Experience of Long COVID in North Central London, April 2022